








## EMPIRICAL RESEARCH QUALITATIVE

# Listen to me, I really am sick! Patient and family narratives of clinical deterioration before and during rapid response system intervention

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## Abstract

**Aim:** To explore patient and family narratives about their recognition and response to clinical deterioration and their interactions with clinicians prior to and during Medical Emergency Team (MET) activations in hospital.

**Background:** Research on clinical deterioration has mostly focused on clinicians' roles. Although patients and families can identify subtle cues of early deterioration, little research has focused on their experience of recognising, speaking up and communicating with clinicians during this period of instability.

**Design:** A narrative inquiry.

**Methods:** Using narrative interviewing techniques, 33 adult patients and 14 family members of patients, who had received a MET call, in one private and one public academic teaching hospital in Melbourne, Australia were interviewed. Narrative analysis was conducted on the data.

**Results:** The core story of *help seeking* for recognition and response by clinicians to patient deterioration yielded four subplots: (1) identifying deterioration, recognition that something was not right and different from earlier; (2) voicing concerns to their nurse or by family members on their behalf; (3) being heard, desiring a response acknowledging the legitimacy of their concerns; and (4) once concerns were expressed, there was an expectation of and trust in clinicians to act on the concerns and manage the situation.

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**Conclusion:** Clinical deterioration results in an additional burden for hospitalised patients and families to speak up, seek help and resolve their concerns. Educating patients and families on what to be concerned about and when to notify staff requires a close partnership with clinicians.

**Implications for the Profession and/or Patient Care:** Clinicians must create an environment that enables patients and families to speak up. They must be alert to both subjective and objective information, to acknowledge and to act on the information accordingly.

**Reporting Method:** The consolidated criteria for reporting qualitative research (COREQ) guidelines were used for reporting.

**Patient or Public Contribution:** The consumer researcher was involved in design, data analysis and publication preparation.

#### KEYWORDS

clinical decision-making, clinical deterioration, medical emergency teams, narrative inquiry, narratives, nursing, patient stories, rapid response systems

## 1 | INTRODUCTION

Unexpected deaths in hospitals have often been preceded by periods of clinical instability that have been missed, misinterpreted, or mismanaged by ward staff (Bhonagiri et al., 2021; Bleyer et al., 2011). To mitigate the risk of serious adverse events such as cardiac arrest and death rapid response systems (RRS) have been implemented globally (Jones et al., 2018; Tirkkonen et al., 2017). A rapid response system (RRS) is the organisational response aimed at improving the recognition and response to clinical deterioration. The responding team within the RRS may be referred to as the Medical Emergency Team (MET) or Rapid Response Team (RRT) (Jones et al., 2017). Responding teams vary in their staffing configuration and may be led by the critical care trained medical or nursing staff Burke et al. (2020). While a growing body of evidence demonstrates the benefits of MET activation for patient outcomes, the delay or failure by clinicians to initiate a MET call remains a serious concern (Bhonagiri et al., 2021; Bingham et al., 2015; Bucknall et al., 2022; Burke et al., 2020; Tirkkonen et al., 2017). Failure to detect and escalate concerns have been ascribed to individual (nurse knowledge and experience) and organisational (staffing levels, skill-mix, interprofessional communication and ward culture) factors (Bingham et al., 2020; Burke et al., 2020; Loisa et al., 2021; Tirkkonen et al., 2017). These individual and organisational factors lead to wide variation in the recognition and response to deterioration (Burke et al., 2020). Furthermore, a failure to recognise, treat and escalate signs and symptoms of deterioration to the MET has negatively impacted patient outcomes (Bhonagiri et al., 2021). On the other hand, patients and their families are often aware of the changes in the patient's condition and therefore, are well placed to advocate for them (Bucknall et al., 2021). Listening to patients and families' perspectives and concerns is a recognised way of improving care that offers further opportunity to address a failure to rescue in clinical deterioration (Bucknall et al., 2021). They provide a unique perspective that may potentially contribute to improving the outcomes of RRS.

### What does this paper contribute to the wider global community?

- A narrative analysis of patients and family stories on their early recognition of clinical deterioration, their experiences raising the alarm and clinician responses to their help seeking.
- An interpretation of patients and families' collective knowledge creates a sequence and meaning that individual participants may not be able to express themselves.
- As a safety function in hospitals, patients and families can play an important role in raising the alarm about patient deterioration.

### 1.1 | Background

Prevention of failure to rescue necessitates the detection, communication and actions of clinical staff. Yet, most literature to date has focused on early recognition of and response to deranged vital signs (Bleyer et al., 2011; Brekke et al., 2019). However, human factors such as staff experience, communication, workload and leadership have been identified as impacting the escalation process both positively and negatively (Ede et al., 2021). In their qualitative synthesis, Ede and colleagues found 16 studies that described the soft signals of patient deterioration including pallor, breathing pattern, blood loss, cognitive changes, fatigue and patient complaints. They reported that few studies have identified more subtle signs were nurses, if they know their patients well, sense something not quite right and may call the MET for being worried (Ede et al., 2021). Even fewer studies have identified the signs and symptoms that ward patients or family members report (Gerdik et al., 2010; Guinane et al., 2018). Yet,

like nurses, patients and families can identify subtle cues of deterioration prior to changes in vital signs becoming evident (Albutt et al., 2017; Gill et al., 2016).

Despite reporting concerns to clinical staff, some patients and families find their concerns are not acted upon. Failure to listen to patients and families has had tragic consequences for some patients, resulting in death and disability (Guinane et al., 2018). As a result, some jurisdictions in Australia, United Kingdom and United States, have advocated for and enshrined the rights of patients and families to escalate their concerns beyond the ward staff (Bucknall et al., 2021). Patient and family activated escalation systems (PFAES) have been implemented to alert critical care outreach teams of patient concerns without mediation by ward staff. In Australia, the implementation of PFAES was driven by the requirement to meet the national hospital accreditation standards (Gill et al., 2016) and assumed that a PFAES would prevent catastrophic outcomes if patients and families had an option to seek additional assistance when their concerns were not met by ward staff. However, knowing when to call and actually calling for help is challenging (Bucknall et al., 2021). Like clinical staff, human factors such as patient and family knowledge and experience of their illness, their ability and confidence to communicate, also influences a patient and family's ability to call (McKinney et al., 2021).

Even with growing evidence of successful implementation of patient and family activated escalation systems PFAES (Albutt et al., 2017; Bucknall et al., 2021) the effectiveness of these systems on improving patient outcomes has yet to be established, and the contribution of patients and families in the early detection of deterioration, has been limited (Albutt et al., 2017; Gill et al., 2016; McKinney et al., 2021). Of nine studies in a review of the effectiveness of PFAES, the quality was rated as low, with a lack of detail reported and justification for sample size absent in most studies (Albutt et al., 2017). Missing in the patient deterioration literature, are studies that analysed the specific triggers and speaking up experiences of both patient and families in hospital wards (Albutt et al., 2017). With growing evidence that consumer involvement in health care decision-making produces safer, more effective, flexible and responsive care outcomes (Bucknall et al., 2020) studies investigating the quality of health care from the patients and families' perspectives are likely to facilitate the development of processes for minimising clinical risks and improving patient safety.

## 1.2 | The study

The aim of the study was to explore patient and family narratives about their recognition and response to clinical deterioration, and their interactions with clinicians prior to and during Medical Emergency Team (MET) activations in the hospital.

## 2 | METHODS

### 2.1 | Design

A narrative inquiry was conducted to obtain the stories of patients and family members of patients who had experienced clinical deterioration requiring MET intervention whilst in hospital. The narrative inquiry produces an account of individuals or groups to make sequences of events meaningful (Polkinghorne, 1988). The narratives involve the collective wisdom of individual stories, distinct events, experienced by individuals and combined into a logical sequence. The interpretation of individual stories allows researchers to analyse the underlying narrative that the individuals may not be able to express themselves (Frank, 2000). The consolidated criteria for reporting qualitative research (COREQ) have guided the reporting of the research.

### 2.2 | Study setting and recruitment

Two major metropolitan Australian hospitals, one private and one public, each comprising over 500 beds and specialist services, were study sites. Both had long established METs without PFAES at the time of the study. Seventy-eight patients were assessed for eligibility (44 private patients; 34 public patients). Patients ( $n=33$ , 17 private, 16 public) and family members of the 33 selected patients ( $n=14$ , 6 private, 8 public) over 18 years old spoke English and were able to articulate their story, identified from hospitalised patients who required urgent medical intervention by a hospital MET were included ( $N=47$ ). Patients were excluded if they were under 18 years old in ICU or clinically unstable on the ward had sudden deterioration ( $<8$ h) were cognitively impaired or had limited English proficiency ( $n=38$ ). Eight hours was selected by the researchers as it allowed time for the patient, family member or clinician to observe and report physical changes or concerns and for the clinician to respond. It encompassed a shift change for nurses, potentially detecting what had been missed previously, and it allowed patients and family an opportunity to communicate changes to another staff member if they were unable to communicate with the previous nurse. There were seven patient refusals to participate.

A purposive sampling technique was used that involved selection of cases to inform the research. Cases were selected based on variation in demographics, patient diagnosis, MET experiences, duration of experience and ability of the patient and family members to express their experiences. A purposive strategy assumed that, given the study aim, different patients and families may hold important and diverse opinions about the issue and therefore, should be included as participants. Initially, a MET registry was reviewed to identify potential participants by a female registered nurse and doctoral candidate researcher (Blinded for review). This was followed by a review of case notes to locate patients who had a period of greater

than 8 h with abnormal vital signs documented prior to the MET call. The researcher (XX) approached the potential participants. The researcher introduced themselves, their role, to establish patient suitability for inclusion and to leave plain language statements (PLS) for patients and family. Recruitment and consent occurred when patients and families had read the PLS, had any questions answered and felt the patient had recovered sufficiently. For each patient participant, a family member was invited to participate; however, participation of a family member was not a prerequisite. Thus, patients were included in the study regardless of their family's decision to participate, or not.

### 2.3 | Data collection

Using narrative interviewing techniques, consenting patients and family members were individually interviewed once clinically stable and had a sufficient time to recover from their MET review. All interviews were audio recorded in private rooms by (Blinded for review) interviews averaged 20 min. The interviewer had no prior relationship with participants. Narrative interviewing begins conversationally with an open and general statement (Mishler, 1986). The intention is to have a statement that opens up the topic and allows respondents to construct a response in collaboration with listeners in a way they find meaningful, whilst encouraging participants to talk freely about their experience (Mishler, 1986). For this study, the opening statement for patients was: *"It seems that your hospital stay has been eventful, what do you understand to have happened to you?"* A similar adjusted statement was used for family members, *"your family member's hospital stay."* Prompts were kept to a minimum and used when required to further explore aspects of the story, such as *"tell me more about..."* Direct questions were avoided to prevent leading patients. Interview recordings were transcribed verbatim by the researcher (XX). No further interviews were conducted once new information, ideas or themes were no longer being revealed in the data. Data was managed in NVIVO software (QSR, 2016).

### 2.4 | Data analysis

A narrative analysis of patient and family member perspectives was used to discover the trajectory experienced by the patients during their deterioration, identify the antecedent events and the activation triggers that eventually led to a clinician response. Two researchers inductively coded the data (Blinded for review) and a third verified the coding (Blinded for review). Narratives allowed the creation of a core story and an emplotment analysis (Polkinghorne, 1988). Core stories condense the story, while emplotment illustrates critical moments in the individual stories (Emden, 1998; Polkinghorne, 1988). Polkinghorne's

human science perspective was adapted by Emden (Emden, 1998; Polkinghorne, 1988). The inductive analysis was further adapted for this study as follows:

1. Multiple readings of the transcripts to understand the content and context;
2. Deleting interviewer questions and comments from the full transcripts;
3. Deleting irrelevant words that detracted from the story;
4. Re-reading the remaining text for sense, ensuring meaning was not lost;
5. Repeating steps three and four until only key ideas remain;
6. Identifying essential themes (sub-plots);
7. Integrating themes (emplotment) to create a core story or a series of stories.

Unlike Emden (1998), participant checks of the transcripts and core story were not conducted as requested by the Human Research Ethics Committee in one of the health services.

### 2.5 | Ethical considerations

Ethics approval for this study was granted by the University (2015-036) and health services (04-24-02-14; HREC/14/192). The interviewer was an experienced female registered nurse with postgraduate research and specialist critical care qualifications. Participation was voluntary. All participants provided informed consent. Any participant who displayed distress during the interviews was asked if they wanted to stop the interview. If after recounting their story, participants appeared distressed they were advised to seek professional assistance and provided with appropriate channels to seek these services.

### 2.6 | Rigour and reflexivity

The authors were guided by Morse's strategies (Morse, 2015) to establish the rigour and trustworthiness of the study findings. For example, a consistent process with each interview was followed, using the same opening question, using similar prompts for more information from the participants. The interviewer had attended a course on the narrative inquiry method and interviewing technique. As a clinician, researcher and a health care consumer, the interviewer was aware of the need to just listen and not put words in the mouths of participants nor steer the interview content. The interviewer made field notes after each interview in a reflexive journal on what went well or poorly in seeking to improve. Interviewer debriefings were conducted regularly by experienced team members. Research team members read verbatim transcripts, familiarised themselves with the stories and participant experiences, developed narratives, refined and checked themes. Researcher biases were clarified, and the findings illustrated using participant quotations.

### 3 | FINDINGS

Participants in this study were patients who had experienced a MET call and family members of patients who had received a MET call. Patients were from one private ( $n=17$ ) and one public ( $n=16$ ) hospital. Six family members were from the private hospital and eight were from the public hospital. Table 1 presents the demographic characteristics of participants.

The experiences of patients and family members of patients who had received a MET call are presented below as a core story of help seeking and a further four, story subplots: identifying deterioration; voicing concern; being heard; and trust and expectation.

#### 3.1 | Help seeking

The core story or plot was one of *help seeking* by patients and family members in response to a perception of being intensely unwell during their hospitalisation. It was an adaptive reaction of feeling worse by seeking help to address their concerns, to solve the problem with clinician assistance. Patient and family stories told of individual surveillance, the escalation to clinicians and family for help and the resolution of the problem. In the background to each story were differing contexts that encompassed the individual patient and family situation, varying social interactions between patients, families and clinicians, organisational policies, and structures. Figure 1 depicts the core story, subplots as a sequence of events and contextual influences surrounding the stories. The recognition of and response to patient deterioration by patients themselves, family members and clinicians yielded four story subplots or themes within the core story. First, identifying deterioration was recognition by patients and family members that something was not right and different from earlier or previous times. Second, was voicing their concerns to their bedside nurse or to family or by family members voicing concerns on behalf of the patient. Third, was being heard, a desire for a demonstrative response that validated their concerns. Fourth, once expressed by either the patient or the family, there was an expectation and

trust in clinicians to act on the concerns and manage the situation. Each of these four subplots will be explained and illustrated with participant quotations.

##### 3.1.1 | Identifying deterioration

Identifying deterioration varied from the recognition of new or changed physical symptoms through to visceral sensations or feelings that remained unreported. Many of the patients identified the onset or a change in physical symptoms but declared they did not understand the clinical significance of their symptoms. Others depended on the family members to call for assistance. The predominant story told by patients was about the onset of pain or changes in the intensity or nature of the pain.

I just started to feel – like my feet started to feel warm and started to swell up or just didn't feel right, and I probably gave it – it was probably an hour I sat with the pain and tried to deal with it.

(Public patient 1)

Other physical symptoms, including feeling cold and drowsy, breathless, dizzy, sweating, shaking, having a racing heart, and nausea were also identified by family members,



FIGURE 1 Illustration depicting the core story, the subplots, the sequence of events occurring within varied contexts. Help seeking is the core story—inner most circle in blue—Level 1. Identifying deterioration, Voicing concerns, Being heard, Trust and expectation are subplots within the core story—Level 2. Stories demonstrated a sequence of events, surveillance, escalation and then resolution, illustrated by Level 3. All stories were told within a variety of wards in differing contexts, illustrated by the outermost circle—Level 4.

TABLE 1 Participant characteristics ( $N=47$ ).

Participant characteristics	Setting	
	Private hospital	Public hospital
<b>Patient characteristics</b>	<i>n</i>	<i>n</i>
Male	9	10
Female	8	6
Age (years)	Median (range) 74 (43–93)	Median (range) 57.5 (26–77)
<b>Family characteristics</b>	<i>n</i>	<i>n</i>
Male	4	5
Female	2	3
<b>Total participants</b>	23	24

She couldn't breathe, she was finding it very hard to even talk.

(Private relative 4)

Physical symptoms were more likely to be reported to the nursing staff:

Hot one minute, cold the next, sweating the next minute. I don't know if that was because I was cold, I was puffing.

(Private patient 12)

Racing heartbeat, I could feel it ... hammering away.

(Public patient 10)

I was just completely sleepy I couldn't wake up.

(Public patient 10)

She was flushed, she was diaphoretic, she was complaining of increased pain.

(Public relative 1)

I honestly thought I was dying. I had enormous pains across the bottom of my abdomen, I was so cold, my whole body was shaking and I was sort of, I couldn't catch my breath, it was just terrible, it was the most terrifying thing that's ever happened to me, honestly.

(Private patient 14)

In contrast, visceral sensations or feelings remained mostly unreported, being described as feeling rotten, really off, not quite right, queasy, anxious, agitated and dopey.

I just had this feeling – that this isn't right. You know, but I didn't think of pressing the button sort of thing, like as if though- I'll shake my head a few times and it will go away. But it didn't.

(Private patient 10)

With an expectation that patients were in the hospital because they were unwell, participants were not concerned nor alert to symptoms that represented a change that should be reported to nursing staff:

I've had pins and plates put into it, it's going to hurt so sort of deal with it.

(Public patient 1)

I said that I didn't feel well and ... sleepy and tired and then she decided to check the blood pressure and then activated the MET.

(Public patient 13)

My wife, daughter and son-in-law were here, they were saying 'Gee you don't look, you're very pasty'. I remember saying 'yes I feel light-headed, yes I feel a little bit dizzy', but when she (the nurse) took my blood pressure, that's when she said – 'How do you feel?' and I said well not too bloody good' I had no idea.

(Private patient 5)

Some were oblivious to their deteriorated condition until the MET arrived, and even after the MET had left, some remained unaware of what had just happened:

I was surprised that they were there. I didn't feel like I was breathing really fast or anything.

(Public patient 9)

It {the MET call} was all over before I knew it began. My only symptom or sign to let me know what was going on was that I had an indwelling urinary catheter and it seemed to me that I had a urinary tract infection.

(Private patient 9)

When some patients were unaware of their changing health status, some family members stepped in and escalated care.

I say 'Oh look, it just might be me, I haven't had a lot of sleep or whatever, but just come and check my husband his, he just doesn't seem to look quite right'.

(Private relative 3)

Most patients and family members were unable to interpret the changes. Instead, they reported the changes to their bedside nurse who, in most cases, responded by initiating assessments and interventions, if indicated.

### 3.1.2 | Voicing concern

Given the subjective nature of symptoms frequently reported by patients, which may have pre-empted objective signs used by clinicians to identify clinical deterioration, a critical juncture in the story was whether, or not, the patient or family member voiced their concerns.

I really wasn't aware that it was perhaps quite so serious. I was getting these waves of dizziness and I just broke out in sweat, almost within. So I, I hit the button and she came back in.

(Private patient 15)



Patients and families ranged from being proactive in their communication through passive recipients of care. The patient's clinical state and personal characteristics were major influences on their ability and willingness to voice their concern of both clinicians and family members:

they were asking me questions and it felt, I couldn't even string my words together properly.

(Public patient 1)

I've always expressed my symptoms when I first come in to how I feel, they would usually ask how I feel and I would describe to them my symptoms.

(Public patient 13)

I tried to catch my breath, it was so severe I actually, literally couldn't breathe. And when I've got myself back into bed is when I called the nurse.

(Private patient 14)

I just started to feel a bit queasy, and I thought I feel like I'm going to pass out, not that that's something - I've only ever passed out once before. But I thought no, I don't feel right, so I pressed the buzzer and the nurse came through.

(Private patient 17)

If too unwell, then patients were unaware of or unable to recognise their deteriorating condition. If able to raise the alarm, most patients called for and told their nurse, pressing their call buttons for help or buzzing continuously if more alarmed by their symptoms until nurses came into the room. By letting the nurse know, the patients perceived they had passed the responsibility onto nurses to decide what to do next:

There's something wrong and she was right onto it... I've had the experience when I had the prostate out.

(Public patient 4)

Patients and family members varied in the way they expressed concern, some had learnt from previous experiences how to identify and report information.

What happened this time has never happened with that bowel prep before.

(Private patient 2)

I was getting a bit worried and then one of the nurses came and I said to her 'She's sleeping, she's sleeping so much', so she goes 'I'll check her blood pressure', and straight away, she didn't yesterday, she just sounded the alarm.

(Public relative 4)

Others were unable to articulate their concerns beyond the notion that something was not quite right. Patients neither want to be perceived as being difficult to complain nor wants to be a burden to a busy nursing staff.

If, when and how patients and/or families voiced their concerns to clinicians was a sliding doors moment in the story, the inconsequential moments that change the trajectory of the event.

But maybe if I had stayed, I would have advocated harder.

(Private relative 3)

If concern was not raised, then the trajectory of clinical deterioration will continue until the objective signs were identified by the clinical staff and escalation was triggered:

they said something about the, my heart rate being very low, as well as the blood pressure was very low and that's what was affecting me...but I was still fairly groggy.

(Private patient 6)

If a patient articulates a concern, it will either result in an action or an inaction. It will be mostly the bedside nurse who will respond by conducting the further assessments. Occasionally, If a bedside nurse failed to respond, The proactive patients and their family members will escalate their concerns to the most senior nursing staff in charge and occasionally to the medical staff.

the actual nurse looking after my wife at the time wasn't too onto it. So I told the ANUM [associate nurse unit manager].

(Public Relative, 1)

If the patients and their family members were familiar with a particular nurse, they will be more willing to share their concerns to that particular nurse and be assured of a response:

I said to the nurse, "Look, this is not normal" and she goes "OK" and this was in a ward where they DO know me, and that makes a big difference.

(Private Relative 3)

### 3.1.3 | Being heard

Patients and families told of a spectrum of responses to their voicing concern. There were nurses who listened, questioned the patient further, assessed them to gain objective data and acted upon their findings.

It was more them [the nurses] asking me questions. They picked up something was going on before I did.

(Private patient 5)

In contrast, other nurses fails to listen, were perceived to have patronising attitudes and fails to respond by undertaking further assessment or even they will indicate that they were hearing the concerns.

I did it [took photo of urine] on purpose because they weren't listening to me. I told the nurse that morning at 7:00 in the morning, "I'm in pain. I've got the pain back. I feel like the infection is progressing. We need to do something, I need to see a doctor." And she said to me, "A doctor will be around." It took five hours for a doctor to come and see me.

(Public patient 16)

I press that buzzer. Sometimes it takes half an hour to get any response. The worst time of the day is changeover ... you press the buzzer and it's bloody hard to get anyone.

(Public patient 5)

Nurses' attitudes were an important influence on the patients' and families' perception of being heard:

I let the nurses know, and that's probably why they were keeping a bit more of an eye on my ob's and stuff like that.

(Public patient 3)

maybe if she didn't come in I probably would have done something I think.

(Public relative 4)

Respecting the messengers and acting on the information by intervening was pivotal:

I guess when they're taking a long time to come it's making you feel a bit unsafe.

(Public patient 9)

Nurse behaviours in response to patient and family member worries did not always acknowledge and act on the concerns appropriately. Slow responses to buzzers, showing a reluctance to intervene, and providing poor access to medical staff when requested by patients and families were barriers to escalation in a timely manner:

I was under the understanding that when you are in hospital you are in a 'safe' place. But things have happened that have made it to be not always a safe place.

(Private relative 3)

Some nurses were made to feel guilty if they did not respond to the concerns.

I would have told her you know said look this is not normal, never seen this before, she's not right and if she had gone away and if I still see that she's not comfortable I would have gone to the nurses' station and say look something's wrong you better do something.

(Private relative 4)

Sometimes patients and families reported waiting until the shift change occurred to re-report the symptoms to their new nurse. The arrival of the MET indicated their concerns were heard and valued:

I felt okay - I thought, no, they're [nurses] onto this ... I felt very reassured when that [MET] happened.

(Private patient 17)

### 3.1.4 | Trust and expectation

When a patient enters a hospital for care, they put trust in the people looking after them. Patients have an expectation that they will be safe and cared in a way that helps them get better.

No I wasn't concerned and because once they turned up I knew they'd fix me up, I've got faith in doctors.

(Public patient 12)

Stories illustrated that trust was always expected but easily eroded.

the registrar came and saw me. She's a junior doctor; she's not equipped to deal with a complex issue. She didn't know. She's spinning - she's not spinning, she's just telling me all your (blood) cultures - she's telling me what I already know. She's not evaluating, she can't assess it. You can't send a junior, that's how I felt; you can't send a junior doctor to assess a situation for a patient because she did get it wrong.

(Public patient 16)

Being listened to and being communicated about plans were a part of the expectation.

The doctor that came down last night, she - after this had all gone through - she spoke to me on a personal level and any questions I had she answered, and if I had any thoughts.

(Public relative 2)

Seeing clinicians performing investigations and interventions increased the trust patients had in the skills and competence of the clinicians caring for them:



then everything happened simultaneously, and she couldn't have been cared for in a better way.

(Public relative 2)

Clinician characteristics influenced relationships. Many of the reported characteristics related to the attitudes that clinicians exhibited rather than the cognitive and technical skills required to respond to the clinical deterioration.

I felt safe because there was a senior doctor that I knew. There were two doctors that you can tell from their posture, their questions, the way they're ordering people around, that they know what they're doing.

(Public patient 16)

If a nurse exhibited confidence, patients were reassured:

they were doing everything you know, and I just left myself to them" (Private patient 10); "I have a lot of faith in the nursing staff here.

(Public relative 1)

'Trust in clinicians was eroded if patients lacked confidence in clinicians responses to the concerns.'

I felt like saying, but was too sick to say, You people let it get to this stage. I shouldn't – we shouldn't have to call this.

(Public patient 16)

Private patients more frequently reported the trust in their clinicians' decision-making and satisfaction with being a passive recipient of care:

you trust people that are looking after you.

(Private patient 9)

Alternatively, public patients expressed more involvement in their care planning.

It's been me letting the staff know... Even if it went by the time they got here, once it reached that one-twenty [beats per minute], that was that point of establishment.

(Public patient 10)

After a MET call, patients felt greater trust in their clinicians. Private patients, although mostly unaware of the reason for their MET calls, felt comforted and confident in their clinicians.

I assumed that something must have happened because so many people arrived so quickly. And so I

assumed some alert must have been put out. I felt okay – I thought, no they're onto this.

(Private patient 17)

Some public patients felt the MET was a safety net, having so many clinicians monitoring their condition and discussing the alternative strategies for treatment was reassuring:

you had 20 people sort of brainstorming over the one problem.

(Public patient 1)

For other public patients, their need for a MET produced new anxiety and a fear of the situation:

you call a MET call because you've lost control. It meant the patient hasn't been managed properly, you've lost control. I don't know whether that's inadequate training on the staff.

(Public patient 16)

## 4 | DISCUSSION

This study demonstrated a new understanding of the types of evidence that patients and families provided to clinicians during episodes of patient deterioration requiring rapid response in an acute care. Patients and families recognised the changes were occurring and were able to communicate their symptoms, experiences and feelings. They wanted a response acknowledging their concerns and trusted clinicians to act on and to manage the situation. Stories revealed the personal surveillance by the patients and their families, their expectations and approaches for escalation. Stories were embedded in a dynamic clinical context, encompassed individual situations, relationships, interactions and organisational processes.

Notably, this study explored both patient and family identification, and experiences in triggering responses of clinicians to acute clinical deterioration in hospital. Very little research focuses on patient symptom reports (McKinney et al., 2021), with even less research focusing on family roles when patients have communication limitations or physical and cognitive impairments (Thiele et al., 2020). We found family members spoke up when patients were unable to recognise a patient's physical changes and themselves experiencing visceral changes or intuitively knowing something was not right. Patients described both the physical changes and the visceral sensations often before nurses detected the vital sign abnormalities. Physical, perceptual and emotional changes have rarely been studied in general ward patients. In two studies, patient reported symptoms included pain, breathlessness, nausea, dizziness, sweating and altered conscious or mental state (Gerdik et al., 2010; Guinane et al., 2018).

Like our study, research on patients' and families' experiences identifying and reporting the deterioration found their capabilities varied and were on a continuum from full awareness and concern to neither awareness nor concern (McKinney et al., 2021; Rainey et al., 2015; Strickland et al., 2019). Similar to Strickland et al. (2019) our study highlighted some patients had a lack of awareness until a nurse identified the issue with them. Understanding the significance of changes, and when and who to report them to, is a challenge for patients and families (McKinney et al., 2021; Rainey et al., 2015). An ability and confidence to speak up is influenced by both individual and external factors. Health status, health literacy and language barriers impact an individual's ability to engage (Bucknall et al., 2004), while previous hospital experiences and chronic medical conditions may increase confidence to voice concerns (Guinane et al., 2018; Rainey et al., 2015). If patients are unable to communicate, then the patient's advocates may be required to facilitate patient and family understanding and preferences for decision-making involvement. In one of the few prospective observational studies, 103 patients were asked to report their level of wellness at the time of observations (Albutt et al., 2020). Patient reports of wellness were found to be a precursor to objective physiological measures of deterioration. Although reports were collected mostly on the patients nearing discharge, this study offers an early evidence on the potential for patients speaking up about their status during routinely collected patient-observations.

Voicing concerns can be difficult due to external factors such as clinical relationships, staff workloads, professional hierarchies and organisational structures (Chung et al., 2022; Rainey et al., 2015). Our study highlighted the importance of the relationship between patients and nurses and critically the communication within that relationship. Chung et al. (2022) also found that one of the most significant factors was the relationship with the health professionals. Speaking up requires psychological safety (Bell & Martinez, 2019). Further, an exchange of information is often context dependent. Bell and Martinez (2019) argue that what is being spoke about matters and differs based on the occasion and reason for speaking up. Positive relationships appeared to support communication about the patient experience to ward nurses. Active communication has been shown to improve outcomes across many areas and to be particularly important in improving patient safety (Bucknall et al., 2020; Vorwerk & King, 2016). In contrast, poor communication has been linked to failure to rescue, delayed or inappropriate treatments and adverse events (Burke et al., 2020; Johnston et al., 2015; Rainey et al., 2015). Rescuing a deteriorating patient hinges on numerous interpersonal interactions that are both complex and dynamic (Smith et al., 2018). A sense of urgency can be perceived differently depending on the qualifications, experience and relationship between clinicians receiving the information (Manolovich, 2022). Whilst the study was conducted at two different health services, private and public, the presentation of the data highlighted the core story and subplots were similar across the both systems. Both the private and public hospitals had established RRSs and METs and were bound by the

same accreditation standards. Nevertheless, some patient and family stories illustrated their hesitation to report because of the staff attitudes, busyness and poor responsiveness by clinicians.

In this study, most nurses treated patient and family reports as evidence and responded by conducting further assessments, making clinical decisions and implementing escalation procedures when indicated. A core element of clinical practice for all the health professionals is listening to patients. However, failure to listen to concerns of patients and families was reported to delay treatment during clinical deterioration by nurses (Strickland et al., 2019). Initiating a response to patient and family concerns reinforced the trust in clinicians and met patient and family expectations. Treating patients and families as knowledgeable allies and partners in care builds trust and promotes continuity of care (Bucknall et al., 2020). In contrast, ignoring concerns, delayed nurses' responses, and failure to initiate an urgent medical response impacted the relationship. Rainey et al. (2015) found staff valued objective information rather than patient reports and failed to treat patients as equal partners in care. Patients and families looked for work arounds to get their concerns heard and acted upon. These delays produced anxiety, frustration and ignored the widely advocated principles of person-centred care. Treating people respectfully as individuals not as a condition. Seeking to understand the preferences of patients, their families and support persons; fostering trust and respectful relationships to share decision-making and plan care, enables person-centred care (ACSQHC, 2023). Although patients and families are heralded as members of the health care team, they are not always given the support, nor authority, to be involved (Bell & Martinez, 2019). They argue that implementing 'speaking up' strategies by patients and families also requires clinicians to 'listen up' and challenge current norms by creating environments for patients and families to speak up.

One approach to improve patient safety, Patient and Family Activated Escalation Systems (PFAES), is being implemented to enable concerned patients and/or family members to call for assistance related to an episode of deterioration that they feel is not being responded to by ward staff (Albutt et al., 2017). Such systems require patients and families to know about, perceive a sense of urgency and feel confident enough to escalate their concerns to clinicians external to the ward. While evidence of PFAES effectiveness is yet to be demonstrated (Albutt et al., 2017; Gill et al., 2016) studies have shown low usage and many calls unrelated to clinical deterioration (Thiele et al., 2020; Vorwerk & King, 2016; Yu et al., 2022). The main reason for PFAES being activated relate to communication breakdowns between ward staff, patients and families. Reporting patient wellness during routine observations, as described by Albutt et al. (2020), is one way of ensuring regular opportunities for patients to raise concerns that may reduce the need for activating the PFAES. Bell and Martinez (2019) argue that PFAES events should be used as learning opportunities for organisations to improve practice and processes. 'Failure to listen (and rescue)' may require identification and management as an adverse event to increase organisational accountability.

## 4.1 | Strengths and limitations

This study was conducted in two major metropolitan teaching hospitals, one private and one public, prior to implementation of PFAES across Australia. While a large sample of patients and family members from two different health systems were included, the stories are personal and as such not generalizable. Patients with cognitive impairment and those with limited English proficiency were excluded due to an inability to consent and a lack of interpreter resources. Such patients may have increased vulnerability and be at a greater risk of suboptimal recognition of the clinical deterioration. To ensure stories offered a trajectory over time, participants were selected after recovery, their recall may have been impacted. Due to physiological disturbance and pharmacological interventions administered to ICU patients, patient and the family stories of participants who had unplanned ICU admissions were excluded; hence, their experiences were not captured. However, in Australia, after a MET call, approximately 86% of patients remain on wards and are not transferred to higher acuity areas such as ICU (Jones et al., 2018).

## 4.2 | Recommendations for further research

This study was conducted in two health services prior to the introduction of PFAES. Since then, implementation of PFAES has expanded and in some countries, it is mandated (Bucknall et al., 2021). However, most research has been conducted at single centres with small numbers. The education and awareness of patients and families varies across wards and health services. Many studies have measured reasons for the calls, satisfaction of patients, and process measures, such as transfer to higher acuity areas, without capturing patient specific outcomes. There is an urgent need to study the effectiveness of PFAES on patient outcomes in multi-site studies given the cost and the sustainability of implementation. Future research could also be directed towards understanding patient and family stories when patients have cognitive impairment or limited English proficiency to add to our knowledge base of experiences and requirements for supporting these patients and families. There remains a lack of evidence on what patients and families requires to be informed more and confident to escalate should the need arise. Research using co-design approaches would address this gap in knowledge.

## 4.3 | Implications for policy and practice

This study reinforced the urgent need to educate clinicians, to promote listening and communicating with the patients and families and to improve the clinical communication. Most research conducted in this area highlights the high number of calls being made related to inadequate clinical communication, which if left unresolved may lead to poor patient outcomes. Similarly, limited medical knowledge inhibits the patient understanding of the significance of symptoms,

so it is important for patients to be educated on admission to hospital of some key signs for them to report and how to report them given the know reticence of some patients to speak up. Co-design of information with consumers has been recommended to improve awareness and correct usage of PFAES (Yu et al., 2022). Evaluation of education programs for both patients and families, needs to be studied for effectiveness. Hospitals need to evaluate their PFAES outcomes specifically measuring the patient outcomes. Lastly, policy makers should be supporting the conduct of research demonstrating effectiveness prior to mandating the interventions in the policy to ensure resources are appropriately directed in the health services.

## 5 | CONCLUSION

This study provides an unique insight into patient and family stories of their experiences leading up to and during the clinical deterioration. The findings offer a narrative analysis of patient and family stories that were used to develop a collective wisdom and create a meaningful sequence around the core story of help seeking. Four subplots were evident, identifying deterioration, voicing concerns, being heard and trust and expectations in a sequence of events that included surveillance, escalation and resolution. The personal nature of the experience requires sharing of information between the patient or their advocate and their nurse to facilitate early escalation and potentially improve patient outcomes. Improving communication between patients, families and health care professionals is the first line of defence for the patient safety and as such, should be prioritised by the organisations to improve patient experiences and mitigate risk.

### AUTHOR CONTRIBUTIONS

Tracey K. Bucknall: Conceptualisation, methodology, project administration, formal analysis, writing-original draft, supervision, funding acquisition. Jessica Guinane: Data collection, formal analysis, investigation data curation, writing-review & editing. Brendan McCormack: Methodology, validation, writing-review & editing. Daryl Jones: Validation, Writing-Review & Editing. Michael Buist: Validation, Writing-Review & Editing. Alison Hutchinson: Conceptualisation, methodology, validation, writing-review & editing, supervision, funding acquisition.

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### CONFLICT OF INTEREST STATEMENT

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

### ETHICS STATEMENT

Ethics approval for this study was granted by the University (2015-036) and health services (04-24-02-14; HREC/14/192).

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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