Patients’ and families’ perspectives of patient safety at the end of life: a video-reflexive ethnography study

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Abstract

Objective: The aim of this study was to investigate patients’ and families’ perspectives of safety and quality in the setting of a life-limiting illness.

Design: Data reported here were generated from a qualitative study using video-reflexive ethnographic methodology. Data were collected over 18 months and generated through participant observation, shadowing of clinicians, field-interviews and semi-structured interviews with patients and families.

Setting: The study was conducted at two hospital sites in Sydney, Australia and in patients’ homes.

Participants: Patients with an advanced life-limiting illness (n = 29) ranging in age between 27 and 89 years and family members (n = 5) participated in the study.

Results: Patient safety remains important to dying patients and families. For dying people, iatrogenic harm is not regarded as ‘one off’ incidents. Rather, harm is experienced as a result of an unfolding series of negative events. Critically, iatrogenic harm is emotional, social and spiritual and not solely technical – clinical misadventure and is inextricably linked with feeling unsafe. Thus, patient safety extends beyond narrowly defined technical–clinical parameters to include interpersonal safety.

Conclusions: Current approaches to patient safety do not address fully the needs of dying patients and their families. Patients and their families regard poor communication with and by health professionals to be harmful in and of itself.

Key words: palliative care, end-of-life care, patient safety, adverse event, communication, patient-centred care, qualitative research

Introduction

Patient safety is defined as the ‘avoidance, prevention, and amelioration of adverse outcomes or injuries stemming from the processes of health care’ [1]. Iatrogenic harm is defined as ‘harm arising from or associated with plans or actions taken during the provision of healthcare, rather than an underlying disease or injury’ [2]. How patient safety and iatrogenic harm are defined, however, has largely failed to account for the socio-cultural context in which healthcare is delivered [3]. Defining patient safety and harm is left almost exclusively to clinicians, policy-makers and researchers [4, 5], with the role of patients and families seen as an emerging area [6, 7]. Rarely are patients or families consulted as to what constitutes ‘patient safety’ and how such harms could be avoided or addressed, yet patients and families hold significant knowledge about healthcare safety and have crucial insights into opportunities for improving care [8]. Previous studies have shown that patients were able to identify adverse events in their own care when not otherwise recorded [9, 10]. Furthermore, the experiences of patients have been
positively associated with patient safety across a range of settings and populations [11].

Patients and families are often actively involved in patient safety even in the face of a life-limiting illness [5]. Safety for people with advanced, life-limiting illnesses may include ensuring adequate treatment of symptoms, and harms may explicitly include failing to manage symptoms. Dietz et al. [12] propose that patient safety for people with a life-limiting illness should encompass key domains of the World Health Organization definition of palliative care including spiritual and emotional as well as physical domains of care. However, we are not aware of evidence from studies that supports these principles [12] or consider the field of patient safety as it relates specifically to palliative and end-of-life care from the perspectives of patient themselves.

This study begins to address this gap. Uniquely, the study aims to ask patients and their families how they themselves define ‘patient safety’ and ‘harms’. Data reported in this paper are a part of a larger ethnographic study to explore the links between the care settings where dying people find themselves, and how these spaces contribute to the safety and quality of the care they and their families receive.

Methods

Theoretical framework

A socio-cultural perspective on patient safety inspired the underpinning theoretical approach to this study. This perspective seeks to investigate the ‘taken for granted’ social elements of patient safety by examining and questioning the assumptions of mainstream patient safety and policy research [13]. This approach embraces organizational complexities and seeks to include notions of patient safety from user perspectives [13].

Video-reflexive ethnography

Video-reflexive ethnography (VRE) is an established methodology [14–16] that seeks to understand the complexity of patient-care delivery as a basis for improving healthcare delivery from the ‘bottom up’ [16]. VRE methodology comprises: ‘video ethnography’: the negotiated videoing of everyday healthcare practices and/or participant accounts of healthcare, and ‘video reflexivity’: the reviewing of video footage with participants to make sense of visual data that they have gathered or feature in themselves [16]. Footage is played back to participants and other stakeholders for review and discussion. Video footage can challenge the taken for granted and attune people to dimensions of practice that they might not otherwise have considered [17].

Setting/participants

Patients and families were initially recruited from a specialist palliative day hospital and subsequently a large Australian tertiary acute hospital. The study follows patients and families prospectively across a variety of care settings including the acute hospital, home, palliative day care and in-patient unit. Participants were recruited using purposive and snowball sampling. Recruitment methods were designed to be as inclusive as possible; that is, not privileging any particular care setting or people with a particular diagnosis. Recognizing the vulnerability of this group of people including fluctuating energy levels and deteriorating function, the researchers aimed to be as flexible as possible so that patients and families could participate on their grounds rather than applying rigid exclusion criteria.

There were three categories of participants:

(i) The patient living with a life-limiting illness.
(ii) The family member(s) of the patient (nominated by the patient for the purpose of this research?)
(iii) Clinicians identified by the person living with the life-limiting illness (not further dealt with in this paper).

Specialty teams (including palliative care, haematology, oncology, respiratory, renal and cardiac) were invited to provide the researcher (A.C.) with details of patients whom they identified as meeting the following inclusion criteria: over 18 years of age; able to converse in English; regarded as having a poor prognosis from the perspective of the treating clinician using the ‘surprise’ question: ‘Would you be surprised if this patient were to die in the next six months?’ [18], and having given consent to the research.

 Institutional ethics clearance was granted from both local health-care and university and institutional human research ethics committees (ref. no.: 2009-264 HREC/08/HNE/434). The study applied an ethics research framework of reciprocity in relationships with patients and families positioning participants’ voices as authoritative and central in the research [19]. In keeping with this framework the consent process was continuous. The researcher provided participants with a written information sheet and the opportunity to contribute to the study at the level of their own choosing. For example, patients could elect not to be filmed. The researcher gained consent for observation, interviews and videoing in person. Consent for video footage was sought both prior and after videoing and prior to being shown to specific reflexive focus group audiences.

A.C., an experienced community palliative care nurse, carried out fieldwork as part of a doctoral study. As an ethnographer, A.C. took a reflexive approach by acknowledging how data collection and analysis might be influenced by the clinical experience of caring for dying people. Not wishing to let theoretical readings nor clinical experience influence study findings, A.C. engaged in self-critique of where behaviours and actions might be being taken for granted.

Data collection and analysis

Patients were asked: ‘Can you tell me about what makes this place safe or unsafe; If you were to make visible to clinicians what is most important to your care what would you want them to see and to know?’ There were several types of data collected as part of the study (Table 1): semi-structured interviews (SSI) [formally, pre-arranged interviews]; field interviews [spontaneous dialogue with patients, family members or clinicians in the field] (‘FF’ from here on); ethnographic field-notes [observation notes written by the researcher] (‘EFN’ from here on) and video-reflexive sessions (‘VRS’ from here on).

Data collection lasted 18 months, with 86 days of ethnographic observations and FI.

SSI and video data were transcribed verbatim alongside FI. Data analysis proceeded concurrently with data collection. Consistent with VRE methods, analysis of data was guided by participants’ input. First, A.C. coded data from Phase 1 to develop initial themes. As part of Phase 2, patients and families were provided the opportunity to view their own footage and to highlight particular clips they wished clinicians to view. A.C. then organized footage into prominent and consistent themes according to patient feedback and informed by themes across all data sets. These emerging themes were then edited into video clips considered representative of these key themes to show back to clinicians (Phase 3) in researcher-facilitated ‘reflexive sessions’ (VRS) as part of a continuous process of immediate critique and comparative analysis. These sessions were also video recorded and used to further refine themes. These sessions provided opportunities for clinicians to discuss opportunities as well as barriers to safe end-of-life care (the specific findings arising from reflexive sessions are reported elsewhere).
Table 1 Data collection and analysis phases

<table>
<thead>
<tr>
<th>Research phases</th>
<th>Data analysis</th>
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<tr>
<td>Phase 1</td>
<td>Level of analysis</td>
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<tr>
<td>Field observations</td>
<td>First-level analysis (coding and development of key themes by the researcher (A.C.) in discussion with research supervisors R.S. and R.I.)</td>
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<tr>
<td>FHN: observation notes written by the researcher</td>
<td>Each participant was provided with an opportunity to view footage in its entirety and to contribute to decisions about which footage to show back to clinicians in VRS</td>
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<tr>
<td>FL: spontaneous dialogue with patients, family members or clinicians in the field</td>
<td>Integration of Levels 1 and 2 analyses</td>
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<td>SSI: formally pre-arranged interviews</td>
<td>Third-level analysis</td>
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<td>Phase 2</td>
<td>Patient insights fed back to clinicians and other stakeholder in reflexive focus groups for collaborative discussion.</td>
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<tr>
<td>Video ethnography</td>
<td>Feedback of footage in these sessions provided imminent critique of researcher derived themes by asking the following questions:</td>
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<tr>
<td>Videoting environments and patient/family; clinician narratives to gain further insight into issues identified in Phase 1. Researcher along with patients and families collected footage</td>
<td>(i) What does the sequence say to you?</td>
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<tr>
<td>Phase 3</td>
<td>(ii) Basic care harms: refers to unmet needs for the activities of daily living;</td>
</tr>
<tr>
<td>VRS with clinicians and other stakeholders</td>
<td>(iii) Symptom management harms: relates to unmanaged pain and other symptoms;</td>
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<tr>
<td>Number of attendees at video-reflexive group sessions ranged from 6 to 28 clinician participants and represented a number of specialties (palliative care, respiratory, surgical, renal and medical oncology/haematology) and disciplines including nursing, medicine allied. Hospital audiences were also provided the opportunity to engage with selected video clips at ‘grand rounds’ events. These sessions with up to 100 attendees followed a similar format to small group sessions</td>
<td>(iv) Environmental harms: refers to concerns about the physical environment;</td>
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<td></td>
<td>(v) Harms associated with care transitions (discharges and transfers);</td>
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<td></td>
<td>(vi) Interpersonal harms: refers to harms directly related to communication and relationships with clinicians.</td>
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RESULTS

Patient participant study sample characteristics

Participants

A total of 45 patients were invited to participate. Sixteen of those patients wished to be interviewed at the bedside without being filmed. Thirty patients consented to being interviewed on film. In keeping with a socio-cultural approach and electing to regard participants as people rather than patients, the researcher did not collect detailed demographic information about participants or their disease. Patients \((n=29)\) ranged in age between 27 and 89 years. A total of five family participants participated directly. All participants had a cancer diagnosis and patient participant and family dyads \((n=2)\) ‘kept’ the camera and provided participant generated accounts. The primary specialty of hospital wards where participants were first seen by the researcher included: respiratory; gynaecology; surgical; medical assessment unit; renal, orthopaedics and oncology/haematology. All but three participants were also known to the hospital specialist palliative care service.

Data analysis yielded several complex insights into patient safety. First, patients and families played a significant role in their own safety [5]. Secondly, patients and families articulated whether they were safe and felt safe in various settings of care including their own homes [20]. Thirdly, and this is the focus of the present paper, patients and families articulated patient safety by speaking about safety in the context of what they saw as the obverse of ‘safety’, or ‘harms’. Our final level of analysis (Table 1) highlighted that to separate or dichotomize safety and harms was overly simplistic; however, we explicate safety and harms themes here merely as a heuristic device.

Specifically, the following six ‘harm themes’ were evident in patients’ observations:

(i) Healthcare-defined iatrogenic harms – an issue for patients and families: participants, to some extent, spoke about iatrogenic harm(s) in the same way that hospital clinical governance departments define and prioritize them such as medication safety, infection control or wrong diagnoses;
(ii) Basic care harms: refers to unmet needs for the activities of daily living;
(iii) Symptom management harms: relates to unmanaged pain and other symptoms;
(iv) Environmental harms: refers to concerns about the physical environment;
(v) Harms associated with care transitions (discharges and transfers);
(vi) Interpersonal harms: refers to harms directly related to communication and relationships with clinicians.

Conversely, patients articulated safety in terms of interpersonal safety underpinned by the following three safety themes:

(i) Teamwork: patients and families spoke not only of their expectation that team members would communicate with each other, but that patients and families should be regarded as central members of that team.
(ii) Enacting agency: refers to patients and families being able to engage with clinicians and act on their own behalf in relation to the safety and quality of care they receive.
(iii) ‘Listening and acting’: patients and families regarded their safety as closely related to being able to express their feelings, concerns and issues important to them, and that clinicians would act upon these concerns appropriately.

Harm themes

Healthcare-defined iatrogenic harms: an issue for patients and families

Patients and families placed value on hospital-defined patient safety even in the last months and weeks of life, and when they themselves knew the patient was dying. For example, medicine safety, including
the storage of medicine as well as receiving the correct medication at the correct time with the correct dose, was high on their agenda:

Why are you (referring to hospital staff) keeping my thyroid tablets in the drawer? They are supposed to be kept in the fridge, ‘No they’re not’. Then they’ve come back in the afternoon and apologised to me (patient). There was a new ruling about keeping them in the fridge (SSI, respiratory ward, patient, acute hospital).

In addition issues of infection control remained important to patients even when their prognosis was poor as the following patient explains:

And, about safety in hospital; infection control; the doctors come around and they go from person to person and they don’t wash their hands. I (patient) always wipe things, handles on doors etc. And their stethoscopes; surely they have something to clean them with in between patients. I think that’s wrong (referring to stethoscopes) (FI, patient, acute hospital).

Importantly, for patients and their families, harm was not limited to what we, the authors, have termed ‘technical–clinical’ defined harm. This harm includes the range of iatrogenic harm identified in national policy documents: healthcare-associated infection; poor medication management; inadequate clinical handover; sub-standard recognition of and response to clinical deterioration, and falls [21]. For patients, in contrast, harm was articulated in a number of additional ways.

**Basic care harms**

Patients and families determined harm to potentially result from healthcare staff not being trusted to meet their basic care needs, such as getting the patient to the toilet, and undertaking care tasks in a timely and competent manner:

Those buzzers are to me an emergency, something’s happened, there’s been an accident of some sort; whether they need to go to the toilet, bathroom or they need a bottle or something like that, that needs to be done there and then. That doesn’t happen when they (patients) press their buzzers in hospitals (SSI, patient’s daughter, surgical ward, acute hospital).

**Symptom management harms**

Harm(s) were defined in terms of clinicians failing to adequately control symptoms.

The patient’s daughter quoted below articulates her frustration to the researcher when she considers that her father has uncontrolled symptoms.

It hit forty three in the afternoon and I needed to get, start making my way home and still no doctor had been up and he’s (patient) got diarrhoea, sweating profusely, severe cramps, pain everywhere and I ended up I walked out and there was a doctor in the hallway and I turned to him and said: ‘Are you a doctor?’ and he said: ‘Yeah’ and I said: ‘Right, you, here now.’ I got him to come in, he (the doctor) assessed him (patient) and everything, and said: ‘Right. I’ll put him down for this, that and the other, a few different things for the diarrhoea, for the cramps and that and some more morphine for the pain. So that was all good, half an hour went by, and the nurse came round and said: ‘Did the doctor come?’ and I said: ‘No, but I managed to get hold of one, but anyway he was supposed to write it down, we’re still waiting, I need to leave. He (the nurse) went and checked and came back and turned around and said: ‘He (the doctor) hasn’t written anything down’ (SSI, patient’s daughter, oncology ward, acute hospital).

The excerpt above shows how a patient’s daughter recognizes her father’s symptoms of pain and diarrhoea and tries to advocate on his behalf. She articulates how repeated attempts to advocate for relief of her father’s symptoms appear to go unheard. The patient is exposed to unmanaged pain and other symptoms causing significant distress. Even when her father’s symptoms are recognized they go unrelieved as a result of what appears to be a breakdown in communication between team members. In the telling of this story, this daughter conveys the harmful effects of these unmet needs on her as well as her father.

**Environmental harms**

The context in which harms took place was important to patients and families. For example, the built environment contributed to whether care was considered of a good quality and safe. Concerns about the physical environment exacerbated patients’ and families’ feeling unsafe. In the next excerpt, a patient evaluates their level of safety based on the cleanliness of the ward as well as availability of healthcare workers to respond to clinical need:

But I have been in terrible wards. There was a ward I was in before that I hated. The toilets were dirty. There were no nurses or doctors to be seen. I couldn’t find anyone to talk to and I hated it. In fact I woke up one morning and said I am leaving and checked myself out. I got up that morning and I thought, I am out of here and I signed myself out. I just got this removed (gestures to intravenous cannulae) and went home (FI, patient, obstetrics and gynaecology, acute hospital).

The patient above determines whether they are safe or not by assessing the physical as well as the social environment. Applying their own expertise, the patient quoted above judged safety to be absent, and took matters into their own hands by initiating their own discharge.

**Harms associated with care transitions**

Harm occurred at times of transition between care environments. Often patients and families with significant experience with hospital care expected their discharge home to be thorough and efficient. The example that follows illustrates how one patient articulates harm at the point of discharge:

And doctor (names staff specialist) came and apologised to me (patient) after throwing me out on Christmas day, which I was very distressed about because I only agreed to have the stent in and go on the warfarin if I had back-up while the warfarin was going and I said. ‘Well what about the warfarin levels?’ ‘Well come to the hospital.’ And I get home and I have no oxygen, nothing (SSI, patient, respiratory, acute hospital).

For the patient above, the harm described directly related to discharge from hospital. The excerpt highlights that iatrogenic harm for this patient was not a single incident but rather a series of harms related to deficient monitoring of their anti-coagulant blood levels and supply of domiciliary oxygen in the context of unplanned and unsafe discharge.

The themes outlined highlight the inter-relatedness of clinical–technical safety with interpersonal safety. Participants often discussed clinical–technical harms in the context of inadequate communication and the effects of that communication. This resulted in what we, the researchers, have named ‘interpersonal harm’. While patients and families considered physical and technical–clinical safety important, these elements of safety are difficult to separate from interpersonal safety. For example, participants frequently spoke about how they often felt being viewed as a disease rather than as a person:
There was one time when I was in hospital and the doctor was looking at the ceiling and I said to him ‘I am not a piece of furniture’. He was completely different the next time he spoke to me. Another time, I said to the doctor: ‘Do you have a mother?’ ‘How would you like your mother to be treated if she was sick like this?’ (SSI, patient, home).

The patient in the excerpt above conveys how clinicians’ objectifying communication sometimes left them feeling unsafe.

Patients and families often positioned themselves as advocates of their own care. When they articulated what they regarded as ‘poor communication’, this was often described in a manner that amplified their own agency in a given situation. Self-advocacy was felt necessary when poor communication was encountered between different disciplines, and between medical specialists as well as with individual clinicians in the team:

Friday, they (the medical team) all come in. I said ‘Right, I’ve been lying here for four days after missing being operated on by (gestures) this much and I am totally bewildered why you have left me lying in this bed and not come and seen me! ‘Aw, we all have to get together’. ‘You have to get together with me. Not just with each other. With me!’ I said: ‘The only problem I have is with your communication at the moment.’ I said: ‘We all have to get on the same page and go . . . on our . . . way (SSI, patient, home).

The excerpt shows how this patient regards them self as a central team member. In sum, patients and families not only articulate communication as being central to the processes that can result in harm but that communication can be harmful in and of itself.

Finally, patients’ and families’ assessment of whether they were at risk of iatrogenic harm or not could have a significant impact on the decisions they took about their care including whether to have a particular treatment or not. For example, the patient quoted in the next excerpt describes how their assessment of level of risk influences their decision about whether or not to have a bone marrow transplant:

Well, I would have a single room, there would be enough nurses to look after me and I would get the correct medicines at the correct time. And it would be clean. They make mistakes all the time with my medicines. I (researcher) asked him how he knew this and he replied that he knew what medicine he takes so he knows when they get it wrong. I (patient) even called 000 one time from my bed because I was at the end of my tether. I just wanted the ambulance to come and take me home. The thing that’s stopping me from having the transplant is my concerns, whether they will be able to look after me properly (SSI, patient, acute hospital).

Patients feel that they must continually monitor clinicians and not take safety for granted. This patient is highly conscious of the errors clinicians are making with medications now that they are no longer in a single room. Their assessment plays a major role in their decision about whether or not to go ahead with a palliative intervention.

Safety themes

Safety: teamwork

To a large extent, and as several of the quotes above (Harm themes) have shown, patients and families presented themselves, not as passive agents of patient safety but as observant of and sometimes actively involved in their own safety. Patients and families not only positioned themselves as members of the healthcare team they also conveyed how this teamwork was necessary for patient safety as the following quote shows:

Well the nurses, all the doctors, your surgeons, your oncologist, your lung specialist and everybody have to communicate together. So that they know the healing process and you know it then that leads into proper caring. If they don’t know, I don’t know, nurses don’t know, we’re in trouble (SSI, patient, acute hospital).

Safety: enacting agency

Patients frequently regarded safety as becoming possible only when healthcare professionals recognized and acknowledged their own knowledge of themselves and were able to enact agency. In the following quote, a patient in the final days of life positions herself as having agency in the context of the research interview:

She (patient) told me (researcher) that she had told ‘them’ (the medical team) Look, I don’t want any of that chemotherapy stuff (non-verbally she (patient) indicates having drips and tubes). You’re not going to do any of that to me unless I decide and after I talk with my family. I just want to go peacefully and with some dignity. This is about me (patient’s emphasis) and my (patients emphasis) body and I’m going to discuss this with my family (field-interview, acute hospital).

This patient draws on past experiences and current resources and the support of her family to retain agency over her life and death. She does not position herself as a passive subject at the mercy of the healthcare team.

Interdependent safeties

Patients described the importance of ‘feeling’ safe or interpersonal safety as indistinct from physical safety and/or safety in terms of their symptoms as this next quote by a patient describing what safety would mean in the last days of life shows:

Well they’d be compassionate, love, consideration, just the experience would be as best and as pain free as possible because that’s what frightens me is the pain. Just that; look after that person as if it’s a member of your family because dignity, you know, being treated properly is important (SSI, patient, home).

Safety: ‘listening and acting’

A safe environment for the person in the next extract is one that enables expression of feelings and opinions:

P: An environment which encourages people to express what they need to express wherever that is, you know, without turning it into a three minute appointment, which you know is how things are often done but that’s the modern world.

R: So what you seem to be saying is that communication that helps you be safe?

P: For me personally yes, but I think, I really do believe its similar for most people, maybe the amount of it, the style of it, may be different but I do perceive it’s the same for most people. Even those who are not whinging they just want share about how they feel, you know (SSI, patient, acute hospital).

Although patients and families like the person above regarded listening in and of itself a key feature of safety, for others safety was only possible when listening translated into action, as the section ‘Harm themes’ showed.

Discussion

The findings outlined above demonstrate that patients’ and families’ experiences and articulations of safety and harm(s) are, to some extent,
consistent with what we term clinical-technical-defined safety and harm (s). Hospital end-of-life care policy documents are, however, often isolated from mainstream safety and quality documents [22]. Yet many patients, even when they are dying, and along with their family members, are concerned with issues such as correct treatment, timely intervention and appropriate infection control just as all patients are. Thus, we argue that these issues require as much attention for people with life-limiting illness whether they have days, weeks, months or years to live.

Significantly, our analysis reveals that patients and families define harm in much broader terms than is common in health service contexts. For them harm includes interpersonal harm and safety. That is, patients and families frame harm, and therefore safety, as emerging from how clinical tasks, interpersonal communication, the built environment and socio-cultural context are intertwined (Fig. 1).

Our findings also point towards harm as defined by patients and families as being not always acknowledged, defined or addressed by clinicians or hospital governance departments and patient safety processes. This may in part be due to patient safety being conceived as avoidance of discrete medical errors associated with specific clinical tasks, and as the prevention by individual clinicians through their adherence to protocols and guidelines [23].

Emerging research in the broader healthcare field shows that safety depends on the ongoing interactions of people with one another [24] and with attention to their structural and socio-cultural surroundings [23, 25]. On this latter view, healthcare workers are continually and contingently defining, redefining and negotiating safety in situ [26–29]. Our findings reveal that patients and families are also continually negotiating safety in situ. They do so often in response to feeling unsafe and deciding they are at risk of iatrogenic harm. Our data show how some patients and families can become actively engaged in patient safety activities [5]. While such level of engagement may be regarded as a positive outcome of clinical professionalism and patient-centred care, it is in fact conditional on clinicians acknowledging that people approaching the end of life are both capable of engaging with patient safety in this way and that they have a right to do so.

Previous studies have established relationships between patient experience, communication and patient safety [11]. The findings of this study support this relationship. Patients place significant value on being able to engage in reciprocal relationships and participate in all aspects of life even in the final days before death [30, 31]. Our study extends these findings by revealing how meaningful and significant interactions are critical to patient safety as people approach life’s end from their own perspectives. In doing so, our findings identified a range of harms that are critically important to patients and families but not accommodated in the definitions of iatrogenic harms commonly used. Emerging evidence suggests that communication can play a significant role in health outcomes and wellbeing [32]. For example, neuroscientists Benedetti et al. [33] have shown that ‘nocebo and/or nocebo-related effects may occur when distrust toward medical personnel and therapies are present’. Most significant, and as we have thus far argued, poor communication may not only result in iatrogenic harm but indeed can, for people approaching the end of life, be harmful in and of itself.

While our study may have relevance for any patient population, iatrogenic harm at the end of life has its own unique and significant ramifications. Patients and their families dealing with life-limiting and/or chronic illness are at increased risk of harm and recurring harms [34]. Iatrogenic harm for an already vulnerable patient may prevent opportunities to deal with end-of-life matters of significance for that person and their family. Iatrogenic harm may place that individual at greater risk of rapid deterioration and may even result in premature death. Given a significant proportion (up to 30%) of hospital inpatients have a palliative intent of care, care of dying people is an increasingly common aspect of patient care [35]. Furthermore, for many people, and at particular times hospital is regarded as a safer place than home [20, 36]. Crucially, this means we need to accommodate notions of safety and harm within the context of dying, and agree

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**Figure 1:** Patient safety model.
on the meaning of patient safety at the end of life, and how it might be accomplished.

Many of the findings in this study speak to the distress caused by harms that are both clinical-technical harms and using the much broader (and appropriate) definitions given by patients and their families. It is likely that many of the issues raised are germane to all other areas of healthcare, and this will need to be explored in future work.

For caregivers such as families and friends, watching someone one loves die is a time that creates a feeling of helplessness. Future research will need to focus on harms in the light of amplifying or magnifying that helplessness. The literature around uncontrolled symptoms having long-term effects on surviving caregivers long after the person’s death now needs to be complemented with the knowledge of what perceived harms (especially if unacknowledged or uncorrected) at the end of life have on the long-term health and wellbeing of surviving family and friends.

**Limitations of the research**

While the researchers did not narrow inclusion criteria to a particular diagnosis, all patient participants had a primary diagnosis of cancer. Patients with non-cancer may define harm(s) differently and therefore would need further clarifying research. Their disease trajectory is likely to be different, as are some of the issues around medication management. A further limitation is that patients who were unable to speak English and patients with cognitive impairment were also excluded from the research. In addition, our study regarded patients and their family members as a unit of care, together representing what patient safety and harm means. However, patients and their families may experience and thus describe and rate safety and quality of care differently [37, 38].

**Conclusion**

The field of patient safety needs to account for and address communication-related harm(s) as well as clinical-technical harms or errors. Future studies should investigate subjecting the kinds of harms articulated in the above findings to the same kinds of accountability and governance that conventional errors are subjected to and explore how safety indicators specific to dying patients and families can be incorporated into health system clinical governance structures [34].

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**Ethics approval**

Institutional ethics clearance was granted from both university and local healthcare institutional human research ethics committees (ref. nos.: 2009–264 HREC/08/HINE/434).

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