

Communicating end-of-life care goals and decision-making among a multidisciplinary geriatric inpatient rehabilitation team: A qualitative descriptive study

Author

Bloomer, Melissa J, Botti, Mari, Runacres, Fiona, Poon, Peter, Barnfield, Jakqui, Hutchinson, Alison M

Published

2018

Journal Title

Palliative Medicine

Version

Version of Record (VoR)

DOI

[10.1177/0269216318790353](https://doi.org/10.1177/0269216318790353)

Rights statement

© The Author(s) 2018. This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial 4.0 International License, which permits unrestricted, non-commercial use, distribution and reproduction in any medium, providing that the work is properly cited.

Downloaded from

<http://hdl.handle.net/10072/413075>

Griffith Research Online

<https://research-repository.griffith.edu.au>

Communicating end-of-life care goals and decision-making among a multidisciplinary geriatric inpatient rehabilitation team: A qualitative descriptive study

Palliative Medicine
2018, Vol. 32(10) 1615–1623
© The Author(s) 2018



Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/0269216318790353
journals.sagepub.com/home/pmj



Melissa J Bloomer^{1,2,3,4} , Mari Botti^{1,2,3}, Fiona Runacres^{5,6,7,8}, Peter Poon^{5,6,9}, Jakub Barnfield^{10,11} and Alison M Hutchinson^{1,2,4}

Abstract

Background: In geriatric inpatient rehabilitation settings, where the goal is to optimise function, providing end-of-life care can be challenging.

Aim: The aim of this study is to explore how end-of-life care goals and decision-making are communicated in a geriatric inpatient rehabilitation setting.

Design: The design is a qualitative descriptive design using semi-structured individual and group interviews.

Setting/participants: This study was conducted in a 154-bed facility in metropolitan Melbourne, Australia, providing geriatric inpatient rehabilitation for older patients; medical, nursing and allied health clinicians, who had cared for an inpatient who died, were recruited.

Data collection: Participants were interviewed using a conversational approach, guided by an ‘aide memoire’.

Results: A total of 19 clinicians participated in this study, with 12 interviewed individually and the remaining 7 clinicians participating in group interviews. The typical patient was described as older, frail and with complex needs. Clinicians described the challenge of identifying patients who were deteriorating towards death, with some relying on others to inform them. How patient deterioration and decision-making was communicated among the team varied. Communication with the patient/family about dying was expected but did not always occur, nor was it always documented. Some clinicians relied on documentation, such as commencement of a dying care pathway to indicate when a patient was dying.

Conclusion: Clinicians reported difficulties recognising patient deterioration towards death. Uncertainty and inconsistent communication among clinicians about patient deterioration negatively impacted team understanding, decision-making, and patient and family communication. Further education for all members of the multidisciplinary team focusing on how to recognise and communicate impending death will aid multidisciplinary teams to provide quality end-of-life care when required.

Keywords

Communication, decision-making, end-of-life care, geriatric, older person, palliative care, rehabilitation

¹Deakin University, Burwood, VIC, Australia

²Centre for Quality and Patient Safety Research, Deakin University, Geelong, VIC, Australia

³Epworth/Deakin Centre for Clinical Nursing Research, Richmond, VIC, Australia

⁴Centre for Nursing Research, Deakin University and Monash Health Partnership, Monash Health, Clayton, VIC, Australia

⁵Supportive and Palliative Care Unit, Monash Health, Clayton, VIC, Australia

⁶School of Medicine, Monash University, Clayton, VIC, Australia

⁷Department of Palliative Care, Calvary Health Care Bethlehem, South Caulfield, VIC, Australia

⁸The University of Notre Dame, Darlinghurst, NSW, Australia

⁹Eastern Palliative Care Association, Melbourne, VIC, Australia

¹⁰Rehabilitation, Aged Persons Mental Health and Residential Services, Clayton, VIC, Australia

¹¹School of Nursing and Midwifery, Monash University, Clayton, VIC, Australia

Corresponding author:

Melissa J Bloomer, Deakin University, Building Y, 221 Burwood Highway, Burwood, VIC 3125, Australia.

Email: m.bloomer@deakin.edu.au

What is already known about the topic?

- Populations of developed countries are rapidly ageing and many older people are living with multiple chronic illnesses contributing to disability, frailty and an increased reliance on health and social services.
- Recognising when a patient is approaching the end of life and diagnosing dying is challenging.

What this paper adds?

- Clinicians in non-acute care settings, such as geriatric inpatient rehabilitation, are inadequately prepared to recognise patient deterioration towards death.
- How patient deterioration towards death is communicated among a multidisciplinary treating team and with patients and/or families is variable.
- Documentation related to care goals and decision-making at the end of life is inconsistent, impacting understanding about the patient's care needs and impending death.
- Clinicians in rehabilitation are ill-prepared for talking with patients and/or family about the likelihood of impending death.

Implications for practice, theory or policy

- Further education is needed for members of multidisciplinary team in focusing on recognising irreversible patient deterioration towards death, and how to adequately communicate and document the findings.
- Improved communication and documentation of care goals and decision-making is essential to improve end-of-life care delivery for the patient and their family.
- Further multicentre research to assess whether these findings are more broadly experienced in other care settings is essential.

Introduction

Populations of developed countries around the world are rapidly ageing.¹ While ageing is viewed as a product of success in public health policy, challenges are created in attempting to address the healthcare needs of older people.¹ Many older people live with multiple chronic illnesses² that contribute to disability and frailty³ and an increased reliance on health and social services.⁴⁻⁶

For older people requiring hospitalisation, care may be provided in a geriatric inpatient rehabilitation setting, which provides medical care and rehabilitation. Australian statistics show that more than 70% of inpatient rehabilitation admissions are for those aged 65 years and above.⁷ Inpatient rehabilitation care is typically co-located with geriatric evaluation and management (GEM) units to form a comprehensive multidisciplinary service for the older person with care aimed at optimisation of the patient's functioning and quality of life.⁷

Despite a focus on rehabilitation, more than 5% of inpatients will die.⁷ A recent Australian audit demonstrated that more than 25% of hospital inpatients have signs indicating they are approaching the end of life,⁸ yet in the rehabilitation setting, clinicians report significant challenges associated with providing end-of-life care. When the focus of inpatient care is on optimising patient function, recognising when a patient

is approaching the end of life is reported as difficult for some clinicians.⁹ Others reported challenges in communication among the treating team in relation to end-of-life care, impacting timely decision-making and care-planning.¹⁰ Lack of guidance for clinicians in the provision of end-of-life care in rehabilitation settings has also been reported.⁴

How patient deterioration and end-of-life decision-making is communicated among the treating team is an important consideration, particularly given the specialised multidisciplinary team approach to patient care in rehabilitation settings.⁷ Treating teams may rely on verbal communication, such as team meetings and/or information documented in patients' written medical records to communicate the plan of care. For example, resuscitation plans, also known as treatment limitation forms, were once used to provide instruction on what to do in the event of a cardiac arrest, but they are increasingly being used as a source of information about the management of other events, including dying.¹¹ Similarly, end-of-life care pathways, similar to the Liverpool Care Pathway, are a complex intervention designed to assist decision-making¹² and facilitate team communication at the end of life.¹³

Recognising the importance of providing safe and high-quality end-of-life care, an Australian government agency,

established to lead national improvements in safety and quality in healthcare, released a Consensus Statement¹⁴ offering acute care providers with guiding principles and recommendations to improve end-of-life care in acute care settings. However, the recommendations do not extend to other care settings such as geriatric inpatient rehabilitation. Further work, focusing on end-of-life care in other settings, is imperative.

Aim

The aim of this study was to explore how end-of-life decision-making and changes in goals of care are communicated in a geriatric inpatient rehabilitation setting.

Methods

The approach was qualitative descriptive,¹⁵ using semi-structured individual and group interviews to gather data.

Setting

This study was conducted in a 154-bed facility in Melbourne, Australia, providing geriatric inpatient rehabilitation care to assist individuals to restore function and attain an optimum level of independence prior to discharge.¹⁶ The facility is part of a larger health service, which provides more than 3.6 million episodes of care annually.¹⁶ The area in which this facility is located has one of the fastest growing older populations in Melbourne, with 9.9% more people aged 70–84 years and 2.8% more people aged 85 years and above, than the rest of Melbourne.¹⁷ The facility was chosen because of the multidisciplinary nature of care and the cultural diversity of the population it serves. While previous research has been conducted in similar rehabilitation settings,^{4,9,10} the size and multicultural nature of this facility make it unique.

Participants

Convenience sampling was used to recruit participants. Medical, nursing and allied health clinicians, aged 20 years or above, employed permanently at the facility, who had cared for at least one patient who had died, were invited to participate. Prior experience or specialist training in palliative or end-of-life care was not a requirement, nor was it a criterion for exclusion. The email invitation to participate was sent to all clinicians employed at the site by a nominated site employee not associated with the study or the research team. Potential participants were asked to self-select by determining their eligibility based on the selection criteria and register their interest via email to an email address created for the study.

Data collection

To maximise participation, potential participants were interviewed individually or in groups, based on their preference and/or availability. Interviews were conducted in meeting rooms or office spaces onsite. Prior to commencement, the purpose of the interview was detailed, questions answered and written consent obtained. A list of guiding prompts was used as an 'aide memoire' to guide interviews. A conversational approach was used during the interviews to encourage open communication between the researcher (M.B.) and the interview participant(s) and to keep the conversation flowing.¹⁸ Interviews were digitally recorded and professionally transcribed.

Data analysis

Prior to analysis, all interview transcripts were checked against the audio recording for accuracy. The transcripts were read and re-read by the lead researcher (M.B.) to get a sense of the whole, prior to analysis. A process of inductive content analysis, where findings were derived directly and inductively from the interview data,¹⁹ was used. This approach attempts to limit the influence of subjective interpretation and/or preconceived outcomes¹⁹ that may be anticipated by the researchers. This approach was considered most appropriate to ensure the findings accurately reflected participants' perspectives. To ensure the validity of the analysis process and findings, a second researcher (A.C.) read the transcripts to get a sense of the whole, derived preliminary themes and then worked with the lead researcher to negotiate and refine the findings. The findings were shared among the research team for open discussion and as part of a quality check, until the final themes were determined.

Ethical considerations

This study received ethical approval from Deakin University (2016-355) and the participating health service (RES-16-0000491 L). In accordance with the ethical approval granted, due to the potentially emotive nature of the topic, participants were informed that they could cease participation in an interview at any time; however, any data already captured as part of a group interview would be used. The confidential nature of group interviews was explained, and group interview participants were asked not to discuss the interview content or other participants after the interviews were completed. Maintaining the anonymity of participants was also of prime importance. Hence, limited details about participants are reported in this article, as a way of ensuring participants remain anonymous.

Table 1. Participants' demographic characteristics.

Role	n	
Registered nurse (manager)	5	
Registered nurse	3	
Enrolled nurse	4	
Allied health clinician ^a	5	
Doctor	2	
Years of experience in setting	Mean	Range
	15	1–40

^aIncludes a music therapist.

Results

In total, 19 clinicians participated in this study, including registered and enrolled nurses, medical staff, allied health staff and a music therapist (Table 1). Of which, 12 participants were interviewed individually and the remaining 7 participated in group interviews. Interviews were conducted in February and March 2017 with interviews lasting between 25 and 41 min (mean = 33 min). Interviews typically commenced with an opening invitation encouraging participants to describe the typical patient and care provided at the facility as a providing context and facilitating introductions. After this opening question, interviews developed organically according to participant responses, with the researcher referring to the interview guide only when necessary. Participant voices are used to exemplify themes. Quotes are labelled according to the interview number and profession.

Typical patient and care provided

In response to the opening question, participants' descriptions of typical patient were diverse. What was common was the sense that the populations were older and frail with complex health needs, for example,

People who have had shocking medical illness ... they nearly always have significant pre-morbid medical baggage. Shocking, often, quite shocking. And they're often slow to recover, if they recover well enough to go home. (Int. 2, Registered Nurse)

Participants also stressed the complex nature of needs for patients in this setting, extending beyond a single medical diagnosis. For example, a doctor described patients in the following way:

... extremely frail ... most of them physically frail, some of them psychiatrically or psychologically frail. We have patients ... [who] have major situations in their life where they can't return home ... a number of very complex issues ... lots of cognitive impairment and lots of risks from frailty such as

falls and pressure wounds ... kind of the milieu here. (Int. 5, Doctor)

When describing care, participants suggested that the nature of care provided in the inpatient geriatric rehabilitation setting had changed, extending beyond the primary focus of improving function and mobility:

It's mostly been known in the past as rehab [rehabilitation], but the nature of health care has driven rehab [rehabilitation] to become sub-acute where people don't need an acute bed. So the focus is working out what this person needs to get home and, if they can't go home, how we're going to help them. (Int. 2, Registered Nurse)

Inductive content analysis of the remainder of the interviews revealed five themes related to how end-of-life decision-making and care goals were communicated: (1) recognising patient deterioration, (2) communicating patient deterioration, (3) communicating with the patient and family, (4) documenting patient deterioration and (5) documents used to communicate or inform end-of-life care. How the themes relate to each other and impact end-of-life care is depicted in Figure 1.

Recognising patient deterioration. Knowing when a patient may be deteriorating towards death was recognised by participants as an obvious first step in providing end-of-life care. For example, one participant described how it can be inherently difficult to differentiate between acute deterioration associated with a reversible cause, and dying:

They can look very similar [to acute deterioration], that's the problem isn't it? I suppose you take in the factors that, usually knowing a little bit about them, but it's really you can see it in the person, they've given up, and that's the key, they've given up, and as soon as that happens, they're on the downhill slope. (Int. 7, Registered Nurse)

Others reported relying on their understanding of the patient's situation and attending to subtle cues in patients' behaviours and physiology to provide a subjective assessment that they may be dying:

I think nurses know better than doctors when patients are going to die, I have to be really honest with you ... you only need to have looked after a couple of patients in the dying phase to recognise the sequences of deterioration, and I think that nurses know very very well. (Int. 2, Registered Nurse)

... you know, like it's just this gut feeling that you've got. (Int. 5, Doctor)

Rather than detailing how dying was recognised, some participants spoke about relying on being informed of the patients' dying status via other means. For example,

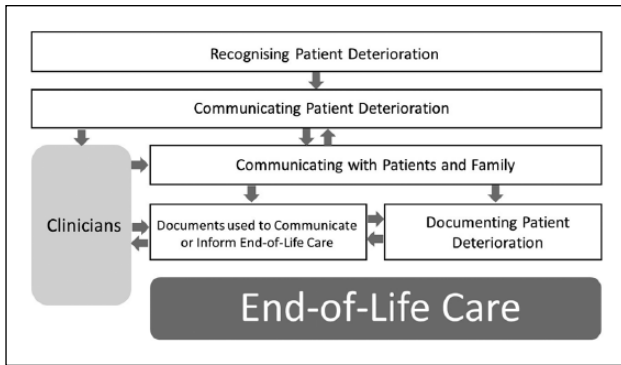


Figure 1. Relationship of themes.

... what their order is, like if someone's say got an NFR [Not for Resuscitation] order or 'not for active treatment' then obviously they're not going to improve if they're in that process of deteriorating. (Int. 8, Enrolled Nurse)

Communicating patient deterioration. When it was recognised that a patient may be dying, how this was communicated to other members of the treating team also varied as demonstrated by the quotes below:

If the nurse feels that that's happening more rapidly than is being recognised, they would always discuss it with me or the senior nurses ... and they would always take it to the doctor ... but they're looking for support. And so I think communication around patient handover is very open and it's a place where we ask lots of questions. (Int. 2, Registered Nurse)

I'll actually write in the notes they've given up, they no longer want to participate, they no longer want to join in, and that's your way of informing whoever's reading your notes, that they're on their way. (Int. 7, Enrolled Nurse)

Another participant, however, resorted to requesting assistance from the medical emergency team (MET) as a way of making other clinicians aware:

So sometimes we'll just call a MET call anyway, just to make sure the doctors are aware ... so that is something I will always try and tell the nurses, that even if it says not for METs, you can call them just to make sure the doctor's aware. (Int. 9, Registered Nurse)

These quotes suggest there may be inherent challenges in effectively communicating clinicians' observations, assessments and opinions, not only between disciplines (e.g. nurse to doctor) but also between levels within the hierarchy of the same discipline (enrolled nurse to registered nurse).

Communicating with the patient and family. In relation to communicating with the patient and family, participants identified that early and unambiguous communication about deterioration and the possibility of death was the

ideal. Nursing and allied health participants explained that doctors are assumed to be primarily responsible for these conversations, as shown in the example below:

I think we need to have a clear cut conversation which can be a team approach or a medical approach, directly to the families. (Int. 1, Registered Nurse)

A medical participant described how seeking the earliest opportunity to commence talking about the likelihood of death was important:

If I expect it or think it's a possibility, when I first meet them on the first conversation, I generally try and break all the bad news. I'll say to them, 'Look, I'm really worried. I think we're going down'. (Int. 5, Doctor)

In contrast, other participants suggested that in some cases, doctors were failing to have timely conversations with patients/family or not spending enough time answering questions or ensuring patient/family understanding:

Because often I think patients don't talk to the doctors. They come in, they're there for two minutes, if that. They sort of talk amongst themselves, don't ask the patient much. They think they're getting their message across but they're not. So there's a miscommunication there as well. (Int. 11, Physiotherapist)

Another described how the haphazard approach to the conversations potentially impacted the effectiveness or clarity of the communication:

I think key discussions with family and patients are not had in a timely or a well-organised fashion. So, sometimes, we may know something from a team perspective that the family may not know – that the doctors feel that they've communicated. You're talking with family or patients and you realise they don't actually get the picture, they don't know that. (Int. 4, Speech Pathologist)

Others suggested that a more opportunistic and informal approach to communication with the patient and/or family was preferred:

... the family, or the patient for that matter, is probably talking first of all to their nursing staff because, you know, it's a one-on-one when you're washing or showering someone, it's that wonderful sort of confessional ... Or an Allied Health, when they're doing on-on-one ... and then, obviously, you can talk about it ... 'have you noticed any changes or have you noticed any changes in dad or mum?' If it's the family, they may bring things to the conversation themselves. (Int. 3, Registered Nurse)

For me it's a matter of – if you can catch them at a certain time, and they know that they're in that phase of they're going to die, you can have those conversations with them. (Int. 7, Allied Health)

Documenting patient deterioration. Participants suggested that it was not always clear when or if patient deterioration and the possibility of dying had been discussed with the patient/family. While the outcome of formal family meetings were typically documented, participants suggested that informal conversations, at the bedside for example, are less routinely documented, impacting the team's understanding:

... we're not actually very good at recording our conversations with relatives, and it's a real weakness ... doctors are having conversations around goals of care and end of life stuff, but I just am not confident ... but really we're underreporting ... we all know that we should, but I just don't know that it's happening as much. So I don't know if we're capturing it. (Int. 5, Doctor)

Acknowledging that written documentation related to communication with the patient/family was poor or inconsistent, participants spoke about relying on other ways through which they could be informed of a patient's status and goals of care:

I'd probably wait until the TPM [team planning meeting] ... to get an understanding of what the medical, nursing plan is ... so that you're all on the same page about what the direction is. (Int. 14, Physiotherapist)

Within handover, that's when I found out, the doctors have said this person's palliative care, they might not make it, that's when I've gone, okay, well. (Int. 7, Enrolled Nurse)

Documents used to communicate or inform end-of-life care. When discussing end-of-life care, participants also readily identified documents in a patient's medical record, which were used to communicate end-of-life decisions or inform end-of-life care delivery.

Treatment limitation form

The treatment limitation form, used to document decisions about limitations to treatment, such as withholding cardiopulmonary resuscitation, was identified by multiple participants. For example,

They're really designed for providing some sort of support or guidance in the care of patients so I think the [documentation of treatment limitations] can help someone who's in that grey zone – the decision-making and what discussions have been had with family and what's in and what's out. (Int. 4, Speech Pathologist)

Another described the form in terms of underlying principles that should inform its completion:

The principles are that the [treatment limitation form] should be based on what the patient brings to the conversation ... but also what the team brings to that conversation on the

basis that the teams are not keen, not interested in providing care that will not be effective, so that's futile. So they will bring that perspective ... [to the completion of the treatment limitation form]. (Int. 6, Doctor)

However, several participants raised concerns in relation to how well the form was used:

I'm not sure that that's always well done. (Int. 4, Speech Pathologist)

I like to think that ... it's pretty good and that people are on the ball, and I'm reasonably confident that that's true. But there would still be patients that don't have the [treatment limitation form completed], either because the patient doesn't want to talk about it, or they've only been here for 24 hours. (Int. 6, Doctor)

Interestingly, one of the medical participants acknowledged the time-sensitive limitations of the form, impacting its relevance:

... we do have discussions with patients and families most of the time. But it's crude in the sense that it makes us document a very certain range, and then as their body changes and our ability to support them or whatever changes, then we are not allowed to, obviously for good reason, modify it. So then we have to redo it. (Int. 5, Doctor)

Dying care pathway

Some participants noted that the Dying Care Pathway (the pathway), similar to a Liverpool Care Pathway, also influenced end-of-life care. However, there were divergent views about the usefulness of the pathway, or whether it was necessary:

If it's going to help the patient or the nurses, then use it. But if the patient's very comfortable and there's no issues and there's no need for analgesia or sedation of any description, then I just think we just do normal good nursing care ... that's where I say to the nurse unit manager, 'Look, if you think the pathway will help the patient, then use it'. (Int. 5, Doctor)

The Geriatricians are reasonably confident in managing someone's dying, and they can provide them with symptomatic care. The junior staff are also reasonably good at that and they can be guided by their seniors. So we don't necessarily need to have a pathway. I think they do use it a reasonable amount. (Int. 6, Doctor)

Further concern was raised that the pathway was being used more as a checklist than a tool to guide care:

I'm not too fussed about whether they use it or not, and in fact, in some ways I'd prefer that they don't. And the reason for that is that they tend to use it as a tick-box, 'Step 1 you do this, Step 2 you do that, Step 3 you do that ... and that's why I'm unhappy when people stop thinking. You should use it as

a guide, you should not be using it as a stepping stone'. (Int. 6, Doctor)

For nursing and allied health participants, the rationale for how and when the pathway was used varied. For example,

Depends on the doctor, or depends on the consultant. If they feel like doing it or not. And I really, really try and push it. Like, really really try and push it. But sometimes you end up arguing with the doctors because they don't want to use it. Personal preference maybe for them, themselves, or they think they can do better. (Int. 9, Registered Nurse)

The consequence for clinicians was lack of clarity about the goals and extent of patient care. A speech pathologist reflected upon this issue in this way:

We sometimes find ourselves in a grey zone ... when the patient's not on the pathway yet but the team are saying, 'Yeah, yeah. They're probably end of life. They're probably, you know, dying. They're not for MET calls. They're not for ICU admission'. But then we still get referred to make these decisions about eating and drinking. (Int. 4, Speech Pathologist)

Conversely, a nurse participant, who had used the pathway many times in her ward, reflected positively on it, saying,

We use the pathway all the time, whenever we have someone identified as being end of life, all of our doctors are really willing to do anything that we want them to do ... because it gives a better guideline of what should be done and it gives consistency. (Int. 7, Registered Nurse)

Discussion

When setting the scene, participants overwhelmingly described a frail older patient population with multiple morbidities and complex physical and social care needs; requiring care that extends beyond the typical focus of care in an inpatient rehabilitation setting.

Main findings

Participants described how providing end-of-life care was inherently challenging in this setting for a number of reasons. The first challenge for clinicians was recognising when a patient was deteriorating towards death, as opposed to an acute deterioration associated with a reversible cause. The diversity of training, scope of practice and specialty focus of members of the multidisciplinary team was likely a contributing factor. While the Australian government¹⁴ has provided recommendations for the delivery of safe and high-quality end-of-life care in acute care settings, the guidelines fail to consider the

added complexities associated with a multidisciplinary team and the nature of care delivery in other settings, such as in this geriatric inpatient rehabilitation facility. The existing recommendations designed specifically for acute care settings cannot be wholly and arbitrarily applied elsewhere.

Effective, concise and unambiguous communication among the multidisciplinary team and accurate and comprehensive documentation are essential to end-of-life care.¹⁰ Yet in this study, participants reported that even when dying was recognised, how, when and by whom this was communicated and documented was inconsistent and sub-optimal, impacting clinician understanding and creating uncertainty in delivery of care for individuals and for the multidisciplinary team. It is acknowledged that with a multidisciplinary team comes varying expertise with dying and death¹⁰ and the identification of patients nearing the end of life is problematic.^{8,20} Nonetheless, all clinicians have a responsibility to clearly document and communicate their role in care provision to other members of the treating team.¹⁴ In the absence of clear information to inform their understanding, participants described other ways in which they could ascertain when a patient might be deteriorating towards death, or what other members of the treating team, such as medical staff, might think, including relying on documents (such as treatment limitation form) in the medical record that were not intended to be the first indicator that a patient was dying.

The treatment limitation form, designed to be completed after consideration of the patient's individual circumstances as an official record of the outcome of the team's informed decision-making,²¹ was instead used by some participants as a way of knowing when a patient was deteriorating or dying. Similarly, in the absence of other indicators, the commencement of a dying care pathway was also used as a signal that a patient was dying. However, opinions varied as to the value and utility of the dying care pathway at this facility. While previous research has endorsed the use of a pathway to guide end-of-life care for older people with complex comorbid conditions,⁹ in this study, participants reported that the pathway was used inconsistently and selectively. The need for ongoing support and education regarding pathway use has been highlighted previously²² and is likely a factor influencing pathway use in this setting. Even though end-of-life care pathways are designed to ensure the most appropriate management occurs at the most appropriate time, by the most appropriate health professional,²³ significant concerns about the safety of implementing end-of-life care pathways exist, limiting their effectiveness.²³ It is possible that similar concerns at this facility impacted its use.

These findings also highlight the obvious need for education for all members of a multidisciplinary team on the

purpose and use of treatment limitation forms and dying care pathways. Clinicians should also be educated and encouraged to use the dying care pathway, which is available across all ward areas, to increase consistency and minimise confusion about end-of-life care.

The way in which participants described communicating with patients and family about patient deterioration was also inconsistent and sub-optimal. With poor communication potentially compromising understanding and trust in the clinician–patient relationship,²⁴ a consistent and coordinated approach to interactions with the patient and/or family is essential to address the information needs of patients and family.^{14,25} The findings stress the obvious need for ongoing education for all clinicians related to communicating with patients and family, to ensure clinicians are adequately prepared to engage in formal and informal conversations with patients/families about dying and end-of-life care as they arise.

Strengths and limitations of the study

In Australia, just like other developed countries, acute hospital and specialist palliative care settings have been the primary focus when considering end-of-life care. Similarly, medical and nursing staff are most often the focus in end-of-life care research. Hence, the strengths of this study are that it was conducted in a geriatric inpatient rehabilitation setting and includes the multidisciplinary treating teams.

It must be acknowledged that the findings of this study represent the perspectives of 19 clinicians from one site. Hence, the findings may not be representative of other clinicians or care settings. Allied health clinicians are proportionally under-represented in this sample. This is thought to be related to how the study was advertised and because potential participants were asked to self-select, it is possible that allied health clinicians did not see the relevance of this study to their role or that their perspective would add value.

What this study adds

This study provides a valuable insight into the challenges of providing end-of-life care in settings where dying and end-of-life care are not considered part of the typical focus of care. Given that death occurs in every practice setting, this study highlights the importance of acknowledging this and preparing clinicians from every discipline. This study demonstrates the need for palliative care education and ongoing support for clinicians working in rehabilitation settings.

Conclusion

Recognising patient deterioration towards death is difficult, and not all clinicians are able or have the necessary

clinical skills to do this. Nonetheless, patient deterioration, whatever the cause, is every clinician's responsibility to recognise and act upon.

Key to facilitating a 'good death' is comprehensive, clear and timely communication. This needs to take place with the multidisciplinary team, the patient and family. Communication of patient deterioration towards death among members of a multidisciplinary team underpins care-planning and a team approach to end-of-life care. In this regard, it is of utmost importance that educational opportunities be developed for clinicians to improve communication skills and learn about patient deterioration, the dying process and end-of-life care.

Given the multidisciplinary nature of geriatric inpatient rehabilitation, the findings also suggest that more work is needed to better understand and articulate the roles and responsibilities of members of this multidisciplinary team in end-of-life care, extending beyond discipline-specific knowledge and contribution. Further multi-centre research to assess whether these findings are replicated at other similar sites and other non-acute care settings is essential.

Acknowledgements

The authors specially thank Anusha Chander, Sotirios (Sam) Xenos and Debra Lonsdale for their contributions to this research. M.J.B. and A.M.H. conceived the study, with input from M.B., F.R., P.P. and J.B.; M.J.B. undertook all data collection; M.J.B. and a research fellow (Anusha Chander) were responsible for data analysis, with further analysis provided by A.M.H., M.B., F.R., P.P. and J.B.; M.J.B. drafted the manuscript; and all authors critically reviewed the manuscript and approved the submitted version.


Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship and/or publication of this article: This study was supported by the Centre for Quality and Patient Safety Research, Deakin University, Australia.

ORCID iD

Melissa J Bloomer  <https://orcid.org/0000-0003-1170-3951>

References

1. World Health Organization. Health topics: ageing, <http://www.who.int/topics/ageing/en/> (2017, accessed 19 January 2017).
2. Centers for Disease Control Prevention. Chronic disease prevention and health promotion: multiple chronic conditions, 2016, <http://www.cdc.gov/chronicdisease/about/multiple-chronic.htm>

3. Hunt KJ, Walsh BM, Voegeli D, et al. Inflammation in aging part 2: implications for the health of older people and recommendations for nursing practice. *Biol Res Nurs* 2010; 3: 253–260.
4. Bloomer MJ and Digby R. Caring for patients dying with dementia: challenges in subacute care in Australia. *J Palliat Care* 2012; 28: 164–168.
5. Digby R and Bloomer MJ. People with dementia and the hospital environment: the views of patients and family carers. *Int J Older People Nurs* 2014; 9: 34–43.
6. Perrels AJ, Fleming J, Zhao J, et al. Place of death and end-of-life transitions experienced by very old people with differing cognitive status: retrospective analysis of a prospective population-based cohort aged 85 and over. *Palliat Med* 2014; 28: 220–233.
7. Australian Institute of Health Welfare. *Australian hospital statistics 2010–11* (Health Services Series no. 43. Cat no. HSE 117). Canberra, VIC, Australia: Australian Institute of Health and Welfare, 2012.
8. Milnes S, Orford NR, Berkeley L, et al. A prospective observational study of prevalence and outcomes of patients with gold standard framework criteria in a tertiary regional Australian hospital. *BMJ Support Palliat Care*. Epub ahead of print 21 September 2015. DOI: 10.1136/bmjspcare-2015-000864.
9. Tan H, Digby R, Bloomer M, et al. Brief report: end-of-life care in a rehabilitation centre for older people in Australia. *Australas J Ageing* 2013; 32: 184–187.
10. Tan H, Bloomer M, Digby R, et al. End-of-life care in an Australian rehabilitation facility for older people: staff focus groups. *Death Stud* 2014; 38: 186–193.
11. Brimblecombe C, Crosbie D, Lim WK, et al. The goals of patient care project: implementing a proactive approach to patient-centred decision-making. *Intern Med J* 2014; 44: 961–996.
12. Deneckere S, Robyns N, Vanhaecht K, et al. Indicators for follow-up of multidisciplinary teamwork in care processes: results of an international expert panel. *Eval Health Prof* 2011; 34: 258–277.
13. Vanhaecht K, Sermeus W, Peers J, et al. The European quality of care pathway (EQCP) study: history, project management and approach. *Int J Care Coord* 2010; 14: 52–56.
14. Australian Commission on Safety Quality in Health Care. *National consensus statement: essential elements for safe and high quality end-of-life care*. Sydney, NSW, Australia: ACSQHC, 2015.
15. Lambert V and Lambert C. Editorial: qualitative descriptive research: an acceptable design. *Pacific Rim J Nurs Res* 2012; 16: 255–256.
16. Monash Health. *Annual Report 2016–17*. Clayton, VIC, Australia: Monash Health, 2017.
17. ID and Community. City of Monash. *Community Profile*, <http://profile.id.com.au/monash/five-year-age-groups> (2017, accessed 1 Jan 2017).
18. Liamputtong P. *Qualitative research methods*. 3rd ed. South Melbourne, VIC, Australia: Oxford University Press, 2009.
19. Moretti F, Van Vliet L, Bensing J, et al. A standardized approach to qualitative content analysis of focus group discussions from different countries. *Patient Educ Couns* 2011; 82: 420–428.
20. Gardiner C, Gott M, Ingleton C, et al. Extent of palliative care need in the acute hospital setting: a survey of two acute hospitals in the UK. *Palliat Med* 2013; 27: 76–83.
21. Smith RJ, Santamaria JD, Holmes JA, et al. Use of resuscitation plans at a tertiary Australian hospital: room for improvement. *Intern Med J* 2017; 47: 767–774.
22. Jackson K, Mooney C and Campbell D. The development and implementation of the pathway for improving the care of the dying in general medical wards. *Int Med J* 2009; 39: 695–699.
23. Chan RJ, Webster J and Bowers A. End-of-life care pathways for improving outcomes in caring for the dying. *Cochrane Database Syst Rev* 2016; 2: CD008006.
24. Hayes B. Trust and distrust in CPR decisions. *J Bioethic Inq* 2010; 7: 111–122.
25. Digby R and Bloomer MJ. Families and caregivers of older people: expectations, communication and care decisions. *Collegian* 2014; 21: 345–351.