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End-of-life care for older people in subacute care: A retrospective clinical audit

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ABSTRACT

Background: With an ageing population and chronic illness the leading cause of death, challenges exist in meeting the healthcare needs of older people. For older people, care may be provided in subacute care services where, although the focus is on rehabilitation and optimisation of functioning, many older people will die.

Aim: To investigate end-of-life care provision for older people in subacute care.

Methods: A retrospective clinical chart audit of all subacute inpatient deaths in one year.

Results: 54 inpatients died in subacute care and almost all had been transferred from an acute care setting. The mean age was 83 (SD = 9), patients had multiple diagnoses and were admitted for assessment or to establish a safe discharge destination. None were identified as 'terminal' on admission and none had an Advance Care Plan to guide care preferences. Prior to death, more than half (57.4%) received terminal care compliant with the Promoting Improved Care of the Dying (PICD) guideline. 53.7% were referred for specialist palliative care review, and despite a mean wait time of 0.6 days (SD = 0.8), 11.1% of patients died before specialist palliative care review. Documentation of communication with patients/family of the likelihood of death occurred in two key sequential time points; the first was information-related and the second decision-related. When these time points occurred impacted end-of-life care provision. Ambiguity in language used to communicate patient deterioration and dying with clinicians and family, impacted understanding and provision of end-of-life care.

Conclusions: Education is needed to aid clinicians in subacute care to identify patient deterioration and dying and communicate the likelihood of death to the multidisciplinary team and with patients and families. Nursing and allied health clinicians are well placed to have greater involvement in communicating patient deterioration and likely death.

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1. Background

Populations of developed countries around the world, including Australia, are ageing rapidly (World Health Organization, 2017). Australians now have among the highest life expectancies in the world (Commonwealth of Australia, 2015), with the proportion of the Australian population aged over 65 years projected to increase from 14% in 2012 to 22% by 2061 (Australian Bureau of Statistics, 2013).

Abbreviations: ACP, Advance Care Planning/Plan; CPR, Cardiopulmonary Resuscitation; EOLC, End of life care; GEM, Geriatric Evaluation and Management; MET, Medical Emergency Team; PICD, Promoting Improved Care of the Dying; SPCS, Specialist Palliative Care Service.

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While ageing is seen as a product of success in public health policy, challenges are also created in attempting to address the healthcare needs of older people (World Health Organization, 2017). Chronic illness is now the leading cause of death worldwide (Centers for Disease Control and Prevention, 2016a), with many older people living with multiple chronic illnesses (Centers for Disease Control and Prevention, 2016b). Older people, particularly those aged 85 years and over (Zhao et al., 2010) are likely to experience a predictable steady decline in health (Bravell, Malmberg, & Berg, 2010). Complex health needs and multiple comorbidities contribute to frailty and disability (Hunt, Walsh, Voegeli, & Roberts, 2010). Cognitive impairment is also associated with significant disability and increased reliance on health and social services (Bloomer & Digby, 2012; Digby & Bloomer, 2014; Perreels et al., 2014).

For many older people, the inability to continue to manage their symptoms and needs at home results in hospitalisation (Johnstone, Hutchinson, & Redley, 2016). Admission to an acute hospital however, represents a critical juncture for frail older adults (Bravell et al., 2010), particularly when acute hospitals are focused on cure, increasing survival and reducing mortality (Bartel, 2016). For older Australians with more complex care needs associated with ageing, care is often provided in subacute care settings (Tan, Digby, Bloomer, Wang, & O'Connor, 2013). Subacute care typically includes rehabilitation, geriatric evaluation and management (GEM) and psychogeriatric care (Australian Institute of Health and Welfare, 2013; Visser et al., 2014), with an average length of stay of 19.2 days compared to 3.0 days in acute care (Australian Institute of Health and Welfare, 2012). This difference in length of stay is attributed to the focus on optimisation of the person's functioning (Australian Institute of Health and Welfare, 2013).

Despite this focus, more than 5% of people admitted to subacute care in Australia die (Australian Institute of Health and Welfare, 2012). In a study conducted in Melbourne over a 2-year period that examined the care of 55 people who died as inpatients in subacute care (Tan et al., 2013), the findings revealed challenges for clinicians in recognising when a patient was approaching the end of life. Further, clinician communication around care planning and decisions was sub-optimal, impacting the type of care provided to patients (Tan, Bloomer, Digby, & O'Connor, 2014). Findings of another Australian study highlighted the lack of guidance for staff in the provision of EOLC (Bloomer & Digby, 2012). Aside from these studies, there is scant evidence to detail how EOLC care is provided in subacute care in Australia.

2. Aim

The aim of this study was to investigate EOLC provision for older people in subacute care. This study was guided by three research questions:

1. What are the demographic and health factors common to those who die in subacute care?
2. How is patient deterioration and likelihood of death communicated between members of the treating team, the patient and family?
3. How could the provision of end-of-life care in subacute care be improved?

3. Setting

The study was conducted in a 183-bed subacute care facility providing a range of inpatient services including rehabilitation, functional restoration, transitional care, aged and mental health care in metropolitan Melbourne, Victoria, Australia (Monash

Health, 2016). With close to 3000 admissions per year (Department of Health Victoria, 2017), this subacute care facility is part of a larger health network that serves more than one million residents or 17% of Victoria's population (Monash Health, 2015). This site was chosen because the area has one of the fastest growing older populations in Melbourne, with 4% more people aged over 65 years and 0.5% more people aged over 85 than the rest of Melbourne (ID Community, 2017).

4. Method

Following ethical approval from the health service (RES-16-0000491L) and Deakin University (2016-355), a retrospective observational audit of all inpatient deaths at the subacute care facility between 01/07/2015 and 30/06/2016 was undertaken. A one-year period was considered to provide an adequate sample size and account for extraneous factors that may influence patterns of dying, such as the seasonal impact on illness. De-identified patient data, including patient demographic characteristics and data related to the duration, location, and type of care were retrieved from existing database sources. Written clinician entries related to the goals/purpose of care, resuscitation limits, and communication of patient deterioration and likely impending death amongst the treating team and with patients and/or families, and decision-making related to EOLC were collected from medical records.

4.1. Analysis

Descriptive statistics were used to analyse quantitative data. Textual data from patient medical records were analysed using qualitative content analysis to address the overall aim of the study.

4.2. Findings

Fifty-four patients died while inpatients in subacute care between 01/07/2015 and 30/06/2016 with an average length of stay of 22 (SD = 11) days. All but five were admitted from an acute hospital ward. The average age was 83 (SD = 9) years and when classified according to the ICD-10 system, 'falls', 'diseases of the circulatory system' and 'problems with life-management difficulty' such as functional decline, were identified as the top three reasons for admission. Almost half had a comorbid diagnosis of dementia or other cognitive impairment. Most were admitted to a GEM bed for 'Assessment' and to 'Establish a safe discharge destination' such as placement in supportive care, and only three were admitted for the purpose of 'Rehabilitation'. For the majority, their child was listed as Next of Kin ($n = 32, 59.3\%$), with the spouse listed as Next of Kin in only 10 cases (18.5%) (Table 1).

None of the 54 patients were identified as terminal/dying on admission; and none had an Advance Care Plan (ACP) in their medical records. Similarly, none of the 54 patients were identified as 'Terminal' on admission on the Treatment Limitation document (see Fig. 1) signed by a medical doctor to indicate the extent of resuscitation in the event of patient deterioration. However, for many of the patients, changes were made to Treatment Limitation document throughout the course of their stay, and by the time patients died, 16 (29.6%) were deemed 'Terminal' and another 37 (68.5%) were deemed not for Cardiopulmonary Resuscitation (CPR) and/or Medical Emergency Team (MET) call (Fig. 1).

Despite deterioration, only 31 (57.4%) patients, or just over half, received terminal care compliant with the 'Promoting Improved Care of the Dying' (PICD) guideline. The PICD guideline was available in all ward areas across the subacute care site, for the purpose of assisting treating teams to manage various aspects of a dying patients' terminal care including pharmacological management,

Table 1
Demographic characteristics and admission data (n = 54).

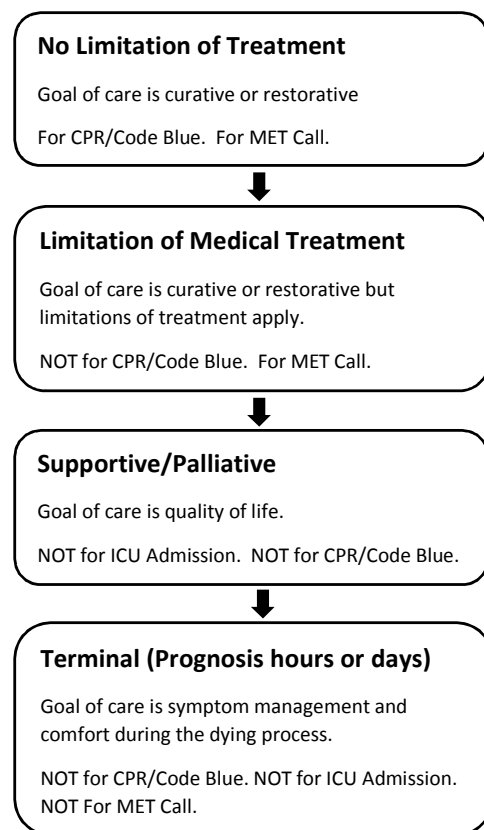
Admission Source	n	(%)
Acute hospital ward	49	(90.8)
Subacute hospital ward	5	(9.2)
Sex		
Male	30	(55.6)
Age at death (years)	Years	(SD)
Mean Age	83	(9)
Range	59–103	
Primary Diagnosis on Admission¹	n	(%)
W00–W19 Falls	15	(27.8)
IX Diseases of the Circulatory System	13	(24.1)
Z74 Problems related to life-management difficulty	6	(11.1)
X Diseases of the Respiratory System	5	(9.3)
XI Diseases of the Digestive System	3	(5.6)
F03 Unspecified Dementia09	2	(3.7)
A41 Other Sepsis	2	(3.7)
XIII Diseases of the Musculoskeletal System & Connective Tissue	2	(3.7)
Z47 Other Orthopaedic Follow-Up	2	(3.7)
XIV Diseases of the Genitourinary System	2	(3.7)
IV Endocrine, Nutritional and Metabolic Diseases	1	(1.8)
II Neoplasms	1	(1.8)
Comorbid Diagnosis of Cognitive Impairment or Dementia		
Cognitive Impairment	15	(27.8)
Dementia	8	(14.8)
Total	23	(42.6)
Assigned Unit of Care		
Geriatric Evaluation and Management	43	(79.6)
Rehabilitation	4	(7.4)
Inpatient Transitional Care Program	7	(13.0)
Care Goal/s on Admission²		
Assessment	39	(47.6)
Establish a safe discharge destination	32	(39.0)
Await bed elsewhere	7	(8.5)
Rehabilitation	3	(3.7)
Management of end-stage disease	1	(1.2)
Total	82	100
Relationship of Next of Kin		
Child	32	(59.3)
Spouse	10	(18.5)
Other family member	4	(7.4)
Friend	5	(9.3)
Legally appointed person	1	(1.9)
Relationship not specified	1	(1.9)
Not documented	1	(1.9)

¹ Primary Diagnosis was determined using the first diagnosis listed, and was coded using the ICD-10 system.

² Several care goals may have been identified for each patient.

family communication and family care. In 29 (53.7%) cases, 22 of whom were receiving care guided by the PICD guideline, a referral was made to the Specialist Palliative Care Service (SPCS) for patient review. The average waiting time between the referral and SPCS review was half a day, yet in six (11.1%) cases, the patient died before the review could take place (Table 2).

Regarding written medical records entries relating to patient deterioration or impending death, considerable variability existed in the number of entries and the level of detail. Almost all written

**Fig. 1.** Treatment Limitation.

entries pertaining to patient deterioration/decline or impending death were written by medical officers. For seven patients however, there were no written clinician medical record entries indicating patient deterioration/decline or impending death.

4.2.1. End-of-life time points

Two key time points relating to the recognition of patient deterioration/decline and impending death were evident in the written clinician entries. *Time point 1 (information-related)* represented the first written evidence of communication with patients and/or families that further rehabilitative or curative treatment was unlikely to be beneficial in restoring health, and that patient deterioration and death was likely. Entries at Time point 1 also typically included terminology such as ‘end-of-life care’, ‘comfort care’, palliative care’, ‘symptom control/management’ or ‘conservative management’. For example:-

Medical entry“...Discussed with [daughter]... [patient] is not improving... I think she is deteriorating in her medical status, worsening failure, short of breath, not eating, likely to have ongoing worsening of failure... [daughter] is aware of prognosis...” (Case 54) Medical entry“...discussed with family – husband and daughter... discussed concerns re progress... discussed guarded prognosis... family not yet ready for palliation and would like to continue treatment for now” (Case 5)

Time point 2 (decision-related) marked the point at which there was a written clinician entry detailing a decision to change care from active management, such as rehabilitation or planning for placement in residential care, to EOLC. For example:-

Medical entry“I have been informed by [name] registrar that she has had a phone conversation with sister in regard to what was discussed today on the [ward round]. We have updated her on his progress and the decision of [doctor] to opt for comfort care only” (Case 6) Medical entry“Clarification of goals of care. Goals: Comfort care ± end of

Table 2
End of Life Decision and Management (n = 54).

Advance Care Plan on Admission	n	(%)
No	54	(100.0)
Treatment Limitation on admission		
Not recorded	1	(1.9)
No Treatment Limitation	1	(1.9)
Not for CPR/Code Blue, But for MET/ICU	32	(59.3)
Not for CPR/Code Blue, Not for MET/ICU	20	(37.0)
Terminal (Prognosis hours or days)	0	(0.0)
Treatment Limitation at death		
Not recorded	1	(1.9)
No Treatment Limitation	0	(0.0)
Not for CPR/Code Blue, But for MET/ICU	6	(11.1)
Not for CPR/Code Blue, Not for MET/ICU	31	(57.4)
Terminal (Prognosis hours or days)	16	(29.6)
Time from final Treatment Limitation decision to death	Days	(SD)
Mean	10.1	(12.5)
Median	5	
Interquartile range	14	
Range	0–61	
Promoting Improved Care of the Dying	n	(%)
Yes	31	(57.4)
Time from PICD Guideline commencement to death (N = 31)	Days	(SD)
Mean	3.4	3.1
Median	3	
Interquartile range	3	
Range	0–15	
Specialist Palliative Care Review	n	(%)
Review requested	29	(53.7)
Review completed	23	(42.6)
Died before review	6	(11.1)
Wait time for Palliative Care Review	Days	(SD)
Mean	0.6	(0.8)
Median	0.5	
Interquartile range	1.0	
Range	0–2	
Evidence of family meetings	n	(%)
Yes	45	(83.3)

life care. Poor prognosis given severe ischaemic cardiomyopathy and likely recent peritonitis (recent cardiogenic shock). Plan clarified with [doctor] with input from [nurse]... family updated (Case 23)

4.2.2. Time point scenarios

In some cases, Time point 1 preceded Time point 2. In other cases, Time points 1 and 2 occurred simultaneously.

Time point 1 precedes time point 2

When Time point 1 preceded Time point 2, the timeframe between the two varied from a few hours to 14 days, providing time for families to receive and comprehend information about patient decline/deterioration and possibility of death, consult with others such as extended family, and begin to arrange family matters and address religious needs. In some cases, Time point 1 occurred early in the trajectory, allowing patients an opportunity to express and share their wishes and preferred goals of care with family and clinicians, and indicate a preference for location of care:-

Case 11–80 year old male was admitted to GEM following Aspiration Pneumonia with multiple comorbidities including pancreatitis, type 2 diabetes, anaemia, stroke, ischaemic heart disease and chronic kidney disease. He was admitted for assessment and to establish a safe discharge destination

Medical entry'Long discussion with son...father deteriorating and decreased communication...No rehab prospects...patient wishes NOT to be kept alive as a "vegetable"...patient has previously indicated he wished to die...sister suggesting withdrawal of NGT (nasogastric tube)...to discuss with brother'Medical entry (next day)'Review with patient's son present...very lengthy discussion with [family] following up on consultant's discussion with him yesterday...[Son] seems to be more accepting of/comfortable with the notion that patient is deteriorating...at the end stage of his life and that current treatment measures are prolonging the inevitable and futile prolongation of life. Plan – cessation of all meds except insulin and feeds...cease active treatment" (Case 11)

Time point 1 and 2 occur simultaneously

This is when the first written evidence of communication with the patient and/or family about the likelihood of patient deterioration towards death also results in a decision to change the focus of care from active management to EOLC. This scenario required the patient/family to accept or contribute to the decision of the treating team, and accept a change to EOLC in the space of one meeting/discussion.

Case 16–96 year old female admitted to a GEM ward with deconditioning secondary to pneumonia, and with a history of aspiration pneumonia, congestive cardiac failure, osteoarthritis, macular degeneration and depression. She was admitted for the purpose of assessment and had been an inpatient for 25 days prior to death. On Day 7, the following entry was noted in the medical record:-

Medical Entry'Discussed with patient's daughter re patient's clinical deterioration and limits of treatment. Explained that worsening clinical status despite treatment along with patient's wishes to no longer receive treatment, that it would be our intention to cease active management and provide comfort care. Patient's daughter in agreement that patient be provided with comfort care given current situation. Plan – commence [dying] pathway" (Case 16)

In some cases however, this may be an unexpected discussion, evidenced by no previous indication of communication with family regarding the patient's declining health:-

Case 21–81 year old male admitted to a GEM ward after recurrent falls, with a past history of delirium, pneumonia, dementia, hypertension, bladder cancer, osteoporosis and alcohol abuse. Patient was admitted for assessment and to establish a safe discharge destination. The patient's admission lasted 30 days, and two days before death, the first documentation of his deterioration appeared in the records:

Medical Entry'Explained that Mr [patient] has deteriorated possibly with another aspiration pneumonia. He is been [sic] provided with comfort measures such as pain and distress management and commenced on dying pathway." (Case 21)

4.2.3. Role and impact of communication

In some cases, clear and unambiguous language was evident in the documentation. For example:

Medical entry'Informed [daughter] that patient is dying, can't be sure if it is going to be today or next few days" (Case 13)Medical entry'informed [family] that patient may not survive this admission" (Case 15)Medical entry'Discussed with son, husband and daughter. Explained gravity of illness, very slim chance of recovery, terminally ill, may likely pass away" (case 45)

In other cases however, the language was ambiguous and did not clearly convey the seriousness of the patient's condition or indicate dying:

Medical entry “Explained that [patient] won’t brighten up” (Case 17) Medical entry “Met with patient’s father earlier today. Explained that he is slowly improving, but will remain frail with very poor reserves, hence poor medium term prognosis” (Case 20) Medical entry “Happy for comfort care in event of deterioration. No change in goals of care” (Case 52) Medical entry “Discussed with son potential to improve or deteriorate. . . unlikely to return to baseline” (Case 41)

5. Discussion

This study has shown that those who died whilst admitted in subacute care, were frail older patients with multiple comorbidities and high care needs. The absence of ACPs in this cohort, and confirmed in previous studies in subacute care (Tan et al., 2014), suggests that pre-hospital EOLC planning may be sub-optimal (Visser et al., 2014). Inadequate community awareness of the need for ACPs, a societal reluctance to discuss EOLC planning and lack of health professional involvement are known issues in Australia (Rhee, Zwar, & Kemp, 2012). The general practitioner is arguably the best person to address EOLC planning, and patients look to their general practitioner to initiate these conversations and often multiple conversations involving the patient and family are necessary (Bloomer, Tan, & Lee, 2010).

When pre-hospital ACP has not occurred, a hospital admission provides an opportunity to consider EOLC planning. Advanced disease, multiple comorbidities, general physical decline, increasing dependence and need for support, and decreasing activity are all indicators that a person may be approaching the end of life (Thomas et al., 2016). Whilst this study demonstrated that treatment limitations were routinely determined for each patient on admission to subacute care, there was no evidence of advanced care planning or end-of-life discussions early in the patient admission process.

When there was acknowledgement of patient deterioration and/or dying, there was variability in how this was documented. Ambiguous language in written medical entries likely contributed to variation in approaches to EOLC, compounded further by inconsistent use of the PICD guideline and SPCS, potentially signalling to members of the treating team that a firm decision had not been made to commence EOLC.

The impact of when the likelihood of patient death was first communicated to the patient and/or family (Time point 1) and when the decision was made to commence EOLC (Time point 2) is also an important consideration. Earlier communication about patient deterioration and dying provided time for the patient and/or family to comprehend the information and may have aided a subsequent decision to commence EOLC.

The absence of written entries from nursing staff pertaining to communication with the patient and/or family about the end of life is also worth noting. Previous research suggests it is not common for nurses to discuss end-of-life issues with patients and/or family (Schulman-Green, McCorkle, Cherlin, Johnson-Hurzeler, & Bradley, 2005), and nurses feel educationally (Bloomer, Endacott, O’Connor, & Cross, 2013; Johnstone et al., 2016) and emotionally underprepared (Bloomer et al., 2013) to talk with patients and family about dying. Given that nurses spend more time with patients than other clinicians (Malloy, Paice, Virani, Ferrell, & Bednash, 2008), nurses are ideally placed to initiate or continue communication with the patient and/or family about the patient’s condition, deterioration and impending death.

5.1. Limitations

A significant limitation of this study was the reliance on retrospective audit. Retrospective audits are limited by the evidence available, in this case, in the patient medical record. It is possi-

ble that patient deterioration and the likelihood of death were discussed amongst the treating team and with the patient and/or family more frequently, and in more detail than what was documented in the medical record. It is also important to note that this study was conducted in one subacute care setting, which forms part of a larger metropolitan health service in Melbourne. Variations in processes and care between this setting and others may occur, however the findings are considered generalisable to the Australian context.

6. Conclusion

The lack of pre-hospital advance care planning and delayed or ambiguous communication about goals of care can result in sub-optimal EOLC. The likelihood of patient decline and death should be anticipated in the frail older population receiving care in subacute care settings. The delay in recognising and acknowledging that a patient may be declining towards death results in delays to re-evaluation of care and the opportunity to commence appropriate end-of-life care to patients. Furthermore, sub-optimal communication at end of life was shown to impact of opportunities to prepare families for impending death. Training and education for all clinicians focusing on communication, specifically the timing, content and clarity of communication of patient assessment, care goals and end-of-life decision-making is urgently needed.

Authors’ contributions

MJB and AH conceived the study with input from MB, FR, PP, and JB. MJB undertook all data collection and initial data analysis with the support of AC (Research Fellow). Further contributing critique and analysis was provided by AH, MB, FR, PP and JB. MJB led the drafting of the manuscript with assistance from AH, MB, FR, PP and JB. All authors critically reviewed the manuscript and approved the submitted version.

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Competing interests

The authors declare that they have no competing interests.

Declarations

Ethics approval and consent to participate: Monash Health in which the research was conducted granted ethical approval for this study (RES-16-0000491L). Ethical approval was also granted by Deakin University Human Research Ethics Committee (2016-355). Consent from the next of kin of deceased persons was waived by the committees.

Consent for publication: Consent from the next of kin of deceased person, whose medical records were included in this study was waived by the governing ethics committees.

Availability of data and materials: The data that support the findings of this study are available from Monash Health, VIC Australia, but restrictions apply to the availability of these data, which were used in this study following ethical approval, and so are not publicly available.

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