A case study approach to investigating end-of-life decision making in an acute health service

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Abstract

Aim.   To identify end-of-life (EOL) decision making processes for patients with non-cancer illnesses in a major metropolitan hospital.

Methods.   A retrospective review using a case study framework of 47 randomly selected patient records over a 6-month period explored issues in EOL care planning.

Results.   Reviewed charts represented 53% of total deaths in the study period. All patients (aged 66–99) had co-morbid conditions. In 64%, the first record of EOL discussions occurred in the last 24 h of life. Four case groups were identified, ranging from a clear plan developed with patient/family involvement and fully implemented, to no plan with minimal patient/ family involvement in decision making. Factors related to clearer EOL care planning according to expressed patient wishes included multiple previous admissions, shorter hospitalisations at EOL, living with a relative and involvement of family in decisions about care.

Conclusion.   This study has shown that the development and effective implementation of EOL plans is associated with the active involvement of both family members and health professionals. It also draws attention to the risks of delaying EOL discussions until late in the illness trajectory or later in life as well as pointing to challenges in acting on EOL developed outside the hospital environment.

What is known about the topic?   End of life (EOL) care planning has been widely discussed in some countries but research into outcomes of such programs has produced variable results both in real outcomes for patients and in satisfaction and ease of application for health professionals. Programs of advance care planning have been introduced in some Australian health services but are yet to produce definitive results.

What does this paper add?   This paper identifies some of the factors that appear to impact on EOL decision making processes in a major Australian metropolitan hospital for patients suffering non-cancer life-limiting illnesses. These data will facilitate the development of more effective EOL care processes in this and other similar healthcare services.

What are the implications for practitioners?   Clear effective processes for making EOL decisions are likely to result in better outcomes for patients, family members and practitioners. A distinctive cluster of patient circumstances may identify risk for poor advance care planning.

Background

Planning for care at the end of life (EOL) is often complex and time consuming. Research into EOL planning in Australia has been limited and the recording of EOL care plans has not been widely or consistently undertaken. In countries where advanced directives are used to articulate patients' wishes, research has

raised questions about the stability of patient preferences,[1] how living wills are used in decision making,[2] and their impact on healthcare costs,[3] although the completion of living wills is associated with lower rates of in-hospital deaths.[4]

Although advance care planning can contribute usefully to EOL decision making it often fails to address major concerns of patients and family members. Significant improvements in EOL care will require shifting the focus from single interventions, such as living wills, to the processes underlying treatment decisions and the development of public policies that use multifaceted interventions to provide competent, coordinated and compassionate EOL care.[5] Studies have investigated patient and family preferences about EOL care, the majority focusing on patients with cancer.[6] These have shown that even where advance directives are in place people dying in institutions often feel inadequately respected, have poor symptom control, and physician communication and emotional support are inadequate.[5] A compounding difficulty when addressing EOL issues for people diagnosed with non-cancer life-limiting illness is the less certain illness trajectories often observed.[7]

One model of care planning, 'Respecting Patient Choices', has been introduced in some Australian healthcare services.[8] However, a literature search found only three publications reporting on outcomes of such applications, in two different major teaching hospitals. Detering *et al.* report on a randomised control trial that found that this model of advance care planning improved EOL care as well as patient and family satisfaction, and reduced stress, anxiety and depression.[9]

The aim of this study was to explore the less investigated area of decision making and care delivery in advanced non-cancer life-limiting illness in order to identify gaps in EOL planning.

Methods

Following human research ethics approval at the health service and Monash University, a retrospective chart audit was undertaken on a random sample of 50 people who had died as in-patients from non-cancer chronic illness over a 6-month period.

The setting for the study was a healthcare network in metropolitan Melbourne, Australia. The region serviced by the hospitals is broadly inner city and urban and the population predominantly of European or Anglo–Celtic ethnic and cultural background. Records were systematically scrutinised and data were recorded in relation to the following categories: age, gender, the number of admissions in the last 3 years, length of stay at last admission, usual place of residence, ethnic origin, religion, palliative care (PC) referral and the existence and date of any resuscitation orders. Medical and nursing notes were reviewed in search of evidence of EOL plans, the processes that gave rise to them, the involvement of patients, their appointed representatives and other family members, and evidence of disagreement within families or between families and medical staff. Although these data were collected by one of the researchers, the research team met regularly to discuss how data were being extracted and interpreted. Data relating to EOL discussions was recorded verbatim from the charts. The use of abbreviations is very common in patient charts and shorthand terms can sometimes mean different things to different people. All such terms used in

the reviewed charts were reviewed and discussed by the research team during the interpretation process.

A process of 'explanation building' as described by Yin (2009)[10] was utilised, aided by descriptive statistical analysis of data (% and means). As Yin suggests, explaining a phenomenon involves stipulating 'a presumed set of causal links about it, or 'how' or 'why' something happened'[10] (p. 141). In a study such as this causal links may be complex and difficult to measure,[10] hence our choice of the case study method. This is an iterative process. The data are examined for links that create clusters or groups of data described as cases. In this study four 'cases' were developed describing different outcomes in relation to EOL planning.

The definition of EOL care planning, used as a lens in examining the data in this study is: a process of planning for care, consistent with a person's values, beliefs and preferences, for that part of life where they are living with and impaired by an eventually fatal condition, even if the prognosis is ambiguous or unknown.[10] This definition was agreed by the reference group supporting the project; a spreadsheet incorporating all categories of data to be collected in the application of this definition to data collection was also approved by the reference group.

Results

A total of 47 patients charts were analysed, the other three being excluded because the primary cause of death was found to be cancer. The sample represented 53% of the total deaths recorded during the study period. It was representative of the total deaths for that period in relation to the distribution of males and females (Table 1) and although the mean age was similar, the age range in the sample was narrower (66–99 years compared with 18–100).

Twenty-nine different diagnoses were recorded and all patients demonstrated co-morbidities. The primary admission diagnosis was most often either cardiovascular or pulmonary in origin. The cause of death was not always recorded. The mean number of admissions in the previous 3 years was 2.7 and the mean length of stay on the last admission was 13.4 days.

The place of residence was identified as 'at home and living alone' (25.6%) 'at home with a partner or relative' (40%), 'at home with another type of carer' (2.1%) and 'residential care' (38.3%).

Only 6% of cases had a resuscitation order on file at the time of the last admission, although 83% had such an order at the time of death. At death, 63.8% of patients had received a referral to PC which occurred on average 2.2 days before death. In 64%, the first recorded EOL discussion occurred within the final 24 h of life. Family support was offered in 57% of cases, 89% of those being referral to a social worker. Notes were brief but evidence suggested that EOL decision making was difficult in conflicted families ($n = 4$) and also when staff and family disagreed about which treatment was futile ($n = 4$). At times ($n = 8$) staff disagreed

Table 1.   Population and sample characteristics

Characteristic	Population	Sample
Total deaths	90	48
Male : Female (%)	51 : 39 (57 : 43)	28 : 20 (58 : 42)
Average age at death	80.8	84.3
Age range (years)	18–100	66–99

with family requests for PC, including in three cases where written orders were either not read or were ignored. Evidence suggested that some families were informed about decisions rather than being involved in the process of making them, without any recorded evidence that the family did not want to be involved.

The data were organised into four composite cases related to the evidence of EOL planning and its implementation (Table 2). The characteristics of these groups were as follows: group 1 (_n_ = 12) comprising those cases that demonstrated clear EOL plans consistent with patient or representative wishes that were implemented; group 2 (_n_ = 14), in which an EOL plan was evident but was not fully carried out, usually due to conflict within the family or between family and staff; group 3 (_n_ = 17), in which

there was some attempt to develop an EOL plan but it was unclear, was inadequately applied and showed lack of patient/family involvement; and group 4 (_n_ = 4), which consisted of cases where such planning was either not evident at all or involved very significant disagreements. Full definitions and key characteristics of the four composite cases are shown in Table 2.

There was no evidence that diagnosis, ethnic origin or religion influenced EOL decision making. Sixty percent of patients were recorded as being 'Australian'; however, ethnic origin was not consistently recorded. In most cases English was recorded as the language of preference, although this appears to be unreliable considering the average age at time of death (84.3) and indications of ethnic origin in which English was not their first language

Table 2. Characteristics of 4 composite cases
EOL, end of life; PC, palliative care

Case group number	Definition	Characteristics
1 (_n_ = 12)	A clear EOL treatment plan consistent with patient or representatives' wishes exists and is adhered to, prepared either well in advance of, or more likely in the few days before, death in the best way possible given time constraints.	• Highest number of admissions in the last 3 years (average 3.8 compared with (cf.) 2.7 overall) • Length of last admission shortest (8.85 day cf. 13.4 overall) • More lived at home with partner than any other group (41.7% cf. 23.4% overall) • All had a resuscitation order at time of death and clear or consistent views expressed either by patient or representative • Communication resolved ambiguities (e.g. guardianship issues, timely confirmation of undocumented patient wishes) • All but one referred to PC • In all cases family or carer consulted about treatment, present with patient and mostly involved in care
2 (_n_ = 14)	A clear EOL treatment plan, which may or may not have been adhered to, or did not have full support of patient, representative or staff throughout treatment time.	• Average number of admissions in the last 3 years (2.5 cf. 2.7 overall) • Length of last admission second shortest (11.9 cf. 13.4 overall) • Least likely to live at home with partner but many at home with other relative • 93% had resuscitation order at time of death (average for total sample 83%) • 71% referred to PC • 50% had evidence of disagreement between staff and family about care, at least initially • 36% of families recorded as 'being present' and 'interested in being involved in care'
3 (_n_ = 17)	Some attempts at EOL care plan, although this may not be clear (terms 'not for active treatment' and 'comfort care' were not considered clear) and may not have been well applied. Evidence of patient or family discussion or involvement may be lacking.	• Average number of admissions in the last 3 years • Length of last admission second above average • Least likely to live at home, most likely to be in residential care • 77% had resuscitation order at time of death – second lowest • 47% referred to PC • 35% evidence of ongoing dissent (family and staff or within family) re treatment • 12% family recorded as being present and interested in being involved in care
4 (_n_ = 4)	Little or no evidence of either a clear EOL treatment plan or of efforts to determine patient or representative wishes, or dissent within family or between family and staff.	• Mean age death >10 years below average • < half average number of admissions last 3 years • Length last admission > twice average • Half lived at home alone • 25% had a resuscitation order at time of death • 25% referred to PC on day of death despite family repeated request for this • 75% little or no family involvement or considerable conflict within the family

(30%). Religious affiliation was recorded as: none 34%, Christian ~50% with the next largest group being Jewish (14%). There was no discussion in the charts about the effect of ethnicity, language or religion on EOL planning.

Comparison of the characteristics of the groups identified four factors that were found to be associated with better outcomes from EOL planning. These were: (1) more frequent admissions in the last year; (2) shorter stay at the last admission; (3) living at home with a partner or caring relative; and (4) active and clear family involvement in decision making.

Discussion

This study has shown that the development and effective implementation of EOL plans is associated with the active involvement of both family members and health professionals. It also draws attention to the risks of delaying EOL discussions until late in the illness trajectory or later in life as well as pointing to challenges in acting on EOL developed outside the hospital environment.

The positive impact of increased contact with health professionals, inferred from a greater number of admissions during the last months of life, is consistent with the outcomes reported by others indicating the importance of effective communication with and trust in the treating physician[6] and time taken to discuss patient and family values and wishes as well as honest discussion of disease trajectory.[9] Teno *et al.*[5] have emphasised, however, that being treated with respect by health professionals is also very important, frequency of contact alone being insufficient.

The presence or absence of active family support and involvement were shown to be very significant factors, along with family dysfunction and differences of opinion about treatment. This is supported by the decline in effective family involvement from groups 1 to 4. The rudimentary nature of the records in many cases regarding family consultation and involvement, beyond statements such as 'family meeting held' or 'family present throughout the night' or 'family involved in care', make it difficult to assess the true nature of family involvement and participation in decision making.

Our results demonstrate that age may influence the readiness of both staff and family members to acknowledge that a person is dying, mean age at death in group 4 being more than 10 years below the overall mean age at death. It is also possible that approaching death is more difficult to accept for a person in their early 70s compared with one in their mid 80s or older, or alternatively that it is perhaps more difficult to recognise a dying trajectory in a younger person. This contrasts to a study utilising a hypothetical experience of a patient in ICU to assess general population attitudes,[11] which demonstrated that older people were less likely to be willing to shorten life in order to have better EOL care. Heyland *et al.*[6] who studied older hospital in-patients did not do subgroup comparisons relating to the age of the patient. The impact of age on effective EOL care planning among the over 65s needs further investigation.

EOL care plans were rare in patients who arrived at the hospital from residential aged care facilities. Three had a documented plan that included resuscitation orders while twelve others from such facilities did not come with these documents. This is significant in the light of efforts to develop EOL plans in such facilities.[12] Nonetheless, the three who did arrive with these documents were not classified in group 1 because in two cases accompanying documents were not accepted as valid and hospital versions were later (by 2 or more days) drawn up without evidence of family or patient involvement. In a third case the patient's EOL care plan (2 months old) stipulating no tube feeding was ignored and restraints were applied to keep the tube in place. This raises the question of whether staff members feel secure following instructions in EOL care plans drawn up outside the hospital and whether documents completed before the current admission reflect the patient's current wishes, both factors previously reported.[1,2] Clearly more work is needed in the development of EOL care plans for residents of aged care facilities that will be accepted and implemented both in the facilities and in the case of hospital admission.

Referral to PC was associated with better outcomes with EOL care planning, as shown by the declining proportions of PC referrals from groups 1 to 4. However, it needs to be noted that the average time of referral to PC before death was only 2.5 days, suggesting that the referral was made only when death was rapidly approaching. The presence of resuscitation orders with varying degrees of detail and/or referral to PC constituted the main evidence for EOL care planning in the charts audited. Possible contributing factors to late PC referral include: (1) delay in recognising approaching death; (2) more complex problems requiring more specialised assistance arising only in the last few days of life; and (3) misunderstanding about the purposes of PC.

Significant limitations were noted in relation to the use of patient charts as a communication tool. Evidence that records were not always read (important discussions repeated on the next shift) and statements such as 'family meeting held' without any comment on the discussion or the decisions, raise questions about the reliability of charts and the extent to which they can be assumed to present a full and accurate record of what actually occurred. In a very large health provider this is of particular concern because the history is an important mechanism for ensuring that patient wishes are widely disseminated to all relevant staff. It is acknowledged however, that the absence of a notation in the chart does not prove it was not done. Similarly what is written in the chart may not give an accurate impression of what was actually done – a concerning situation from the perspective of communication, but one that places limitations on conclusions that can be drawn from the retrospective chart audit.

A limiting factor in this study was the modest number of charts examined, particularly in group 4. Nonetheless, the detailed analysis of the histories provides an important and novel insight into the ways in which EOL planning is communicated and recorded in the hospital setting.

Conclusion

Trust in, and positive communication with, health professionals as well as the active involvement of family or surrogate decision makers, are associated with the effective development and implementation of EOL care plans. Other important factors include the age of the patient and timely referral to PC. More work is needed on the effective development and implementation of EOL care planning in aged care facilities as these relate to hospital admission.

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