When death is imminent

Documenting end-of-life decisions

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Background

There has been widespread promotion of advance care planning in recent years, which is consistent with an ageing population and a greater awareness of patient self determination.

Methods

A review of medical records relating to hospital patient deaths and a separate review of emergency department admissions of patients aged 75 years or more in the same hospital.

Results

In the patient deaths sample, 77% of patients (median age 79 years), had their first documented end-of-life discussion 3 days before death. In the sample of emergency department admissions, 82% of patients (median age 83 years), had no documented end-of-life discussion or review by the time of discharge. Only two patients, both in the emergency department admissions group, had written advance care plans before admission.

Discussion

This study suggests that documented advance care plans are either not being prepared in the community or are not being communicated to acute care facilities. As a result, end-of-life care preferences are documented when death is imminent.

Keywords

advance care planning; inpatients; aged

In recent years, advance care planning has been widely promoted to health professionals and the general community. Advance care planning has the potential to promote patient self determination and ease concern about loss of control.[1] Families also benefit from advance care planning, demonstrating less stress, anxiety and depression and reporting greater satisfaction with the quality of death of their family member.[2] Health professionals have been shown to find involvement in end-of-life (EoL) care more satisfying when they know the care that they provide is informed by an advance care plan and consistent with the patient's wishes.[1]

While advances in medical science enable health professionals to prolong life in some cases, a majority of aged care facility residents nearing EoL in 17 residential aged care facilities (RACFs) in Melbourne (Victoria) preferred not to be moved to acute care but rather to receive palliative care from familiar staff in the facility.[3] Providing resuscitation and life sustaining interventions to very sick, infirm or terminally ill patients where comfort measures may have been more appropriate, may cause grief among relatives when it is done against their wishes or against the expressed but undocumented wishes of the patient.[4] However, as a result of an ageing population, the inability to make and communicate decisions towards the EoL is increasingly common. The high proportion of noncompetent patients aged 80 years and more admitted to hospital,[2] and the projected growth of dementia in the total population from 1.2% in 2010 to 1.9% in 2030 and then 2.8% in 2050,[5] highlight the importance of conducting advance care planning while patients are still competent to do so.

The widespread promotion of advance care planning means that the number of documents providing guidance in New South Wales Health and associated primary, community and residential care sectors may be impeding their confident implementation by health professionals.[6] Many government health services and health organisations across Australia include advance care planning information and tools in their online resources. A review by the lead author in June 2011 identified that at least 80% of metropolitan, regional and rural local health districts in New South Wales, and 58% of the 33 divisions of general practice have some form of advance care planning content on their websites.

However, it is not clear that this promotion of advance care planning has had an impact. This study reports the prevalence and type of documented EoL decisions in a population of patients nearing EoL admitted to acute care in a regional hospital in New South Wales.

Methods

Tamworth, the major city in northwestern New South Wales, has a population of over 50 000.[7] The proportion of residents aged 75 years and more living in Tamworth (7.4%) is greater than that across the state as a whole (6.6%).[8] Tamworth is serviced by one public hospital facility, Tamworth Rural Referral Hospital (TRRH).

A retrospective review of hospital medical records of patients who died in TRRH from 1 January to 31 March 2011 and a separate review of unplanned admissions through the emergency department (ED) in TRRH during the same period was completed. The two sample groups were chosen to contrast the prevalence of EoL decisions in a population at EoL (patient deaths) to a population that could be considered nearing EoL (ED admissions). The review only examined patient documentation in their hospital medical record. No primary care documentation was examined. Two reviewers (AG and SD) reached consensus on whether an EoL decision was documented and the type of decision using the descriptors in *Table 1*. The type of decision was subclassified based on whether the patient, person responsible or doctor had provided input to the decision.

Medical records of patient deaths were selected based on the premise that those very close to death were more likely to have expressed their EoL preferences. Inclusion criterion was patients who died in TRRH during the study period. Exclusion criteria were death from sudden trauma (not as a consequence of an age or end stage related condition) and paediatric patients.

Medical records of older patients that had an unplanned admission through the ED were examined, as this demographic was thought by the authors to be typical of patients with relevant advance care planning indicators including advancing age, chronic conditions, comorbidities, repeat hospital admissions and residence in an aged care facility. The inclusion criteria were patients admitted to a ward after presentation to the ED during the study period and aged 75 years or more. Admissions less than 24 hours were excluded.

Data relevant to EoL decision making was collected, including patient demographics, admission duration; the incidence and type of pre-existing EoL decisions; the incidence, timing and type of EoL decisions made during admission; who was involved in EoL decisions; and whether an EoL medical order was completed. Descriptive statistics were used to summarise and contrast the two sample groups.

This study was granted ethics approval by the Hunter New England Research Ethics and Governance Unit.

Results

Forty-three medical records were reviewed of the 80 patient deaths during the study period. The other 37 records related to excluded patients or were not readily available as they were being used for other purposes (eg. morbidity and mortality reviews). For the ED group, 55 medical records meeting the inclusion criteria were available from the TRRH medical records department and were reviewed.

Table 1. Classification of end-of-life decisions

Type	Description
End-of-life	EoL record made by the treating medical practitioner that orders limitations or withdrawal of life prolonging medical interventions
Doctor limited	EoL record made without input from the patient or their person responsible that records the order without rationale or evidence behind the decision
Doctor detailed	EoL record made without input from the patient or their person responsible that records the order with detailed rationale or evidence behind the decision
Patient	EoL record made with input from the patient
Person responsible	EoL record made with input from the patient's person responsible
Advance care plan	Advance care plan may be established by discussion or in writing to guide decisions about care made on the person's behalf and may identify the person responsible and/or preferences in relation to health and personal care and preferred health outcomes
Not TRRH	Advance care plan generated outside TRRH
TRRH form	Advance care plan written on the Hunter New England Advance Care Planning Discussion Record that records the outcomes of advance care planning discussion with the patient
TRRH notes	Advance care plan written in the patient's progress/clinical notes that records the outcomes of advance care planning discussion with the patient
Advance care directive	Advance care directive contains instructions that consent to, or refuse, specified medical treatments in the future
Not TRRH	Advance care directive generated outside TRRH
TRRH form	Advance care directive written on the Hunter New England Advance Care Planning Discussion Record that records the outcomes of advance care planning discussion with the patient
TRRH notes	Advance care directive written in the patient's progress/clinical notes that that records the outcomes of advance care planning discussion with the patient

For both sample groups, key characteristics are presented in *Table 2* and the types of documented EoL decisions are presented in *Table 3*. The findings did not facilitate analysis to determine if this variation was statistically significant. A number of characteristics are (reasonably) consistent across both groups. The majority of all patients sampled were admitted from the community, rather than an RACF or other health facility, with close to half admitted to TRRH more than once in the previous 12 months. While a small number in each sample (n=7 in both groups) were admitted with a previous EoL treatment decision, most of these decisions were reviewed on the most recent admission and the patient was generally involved in that review. Only one patient overall was admitted with a documented EoL discussion with their general practitioner. No patients in the patient deaths sample were admitted with an advance care plan or directive and two patients were admitted with an advance care directive in the sample of ED admissions. One of the six patients admitted from an RACF in the ED admissions sample had a previously documented EoL decision compared to three of the 6 patients in the patient deaths sample.

Not unexpectedly, the key differences between the two sample groups were that a larger proportion of patients in the patient deaths sample (77%) had an EoL discussion documented by a medical practitioner in acute care for the first time during the most recent admission compared to patients in the ED admissions sample (11%); and that there was a much greater proportion of family conferences in the patient deaths sample (70%) compared to ED admissions (11%). For those in the patient deaths sample, postadmission EoL decisions were first documented when death was imminent (median 3 days before death).

Discussion

Medical practitioners in both primary and acute care are generally aware when their patients are nearing EoL. For patients in this study, a population in which death was presumably not unexpected, discussion about EoL treatment preferences was not documented for consideration in acute care until the last days before death. Given their stage of life, patients in this study were likely to have been under the care of a GP, however, consistent with other studies there was limited evidence of preparations for EoL healthcare[4,9,10] and extensive use of acute care services in the last year of life.[11] Based on this study, in populations in which death is not unexpected, decisions concerning EoL treatment preferences are either not being discussed and documented in primary care or these decisions/documents are not being provided to acute care facilities on admission. Further, despite reported preferences for self determination and autonomy, this study indicates that EoL decision making is driven not by patients, but by acute care medical practitioners and only out of necessity.

The lack of documented advance care planning and the requirements of acute care necessitate EoL decision making in acute care that focuses on specific medical interventions. In this study, there was little evidence that acute care practitioners took time to explore the patient's personal values in terms of acceptable outcomes when nearing EoL or that these were considered when making decisions.[12] Rather, documented decisions were narrowly focused on medical interventions and the generation of medical orders for the withholding of life prolonging treatment. This narrow focus is not surprising given the context of the discussion and the pressing requirement to make decisions about life prolonging treatments when managing deteriorating patients. These types of decisions, while prevalent, are not advance care planning.

It is recognised that some standardisation of advance care planning documents may overcome some of the difficulties currently faced by practitioners when interpreting the plethora of advance care plans.[6] However, research has promoted a move away from advance care planning that focuses on the documented refusal of life sustaining medical interventions,[13] to an ongoing process of discussion that involves substitute decision makers and explores a person's values and goals of care as they approach EoL.[2,14,15] These more abstract concepts are better understood by patients, most of whom do not really understand the range of medical interventions nor how and when they may be used or their consequences.[2] The GP is best placed to facilitate the uptake of advance care planning by initiating these discussions as part of the norm in the treatment of their patients nearing EoL. Primary care is a more conducive environment for this discussion, and is consistent with the concept that planning for EoL is a natural part of the continuum of care provided by GPs.[11] Further, most patients would prefer to have this discussion

Table 2. Patient characteristics

Characteristics	Patient deaths n (%)	Emergency department admissions n (%)
Sample size	43	55
Median age (years)	79	83
Female	25 (58)	39 (71)
Admitted from community (not aged or other care facility)	27 (63)	46 (84)
More than one admission previous 12 months	24 (56)	26 (47)
Median bed days before death or discharge (days)	6	4

Table 3. Types of documented end-of-life decisions

Type of decisions	Patient deaths n (%)	ED admissions n (%)
Sample size	43	55
Previously documented EoL decision	7 (16)	7 (13)
Previously documented EoL decision reviewed during current admission	6 (86)	4 (67)
Advance care plan or directive on admission	0 (0)	2 (4)
First EoL decision documented during admission	33 (77)	6 (11)
The EoL decision made with input from the patient	19 (44)	3 (5)
The EoL decision made with input from the person responsible	16 (36)	2 (4)
The EoL decision made with input from the doctor only	5 (12)	1 (2)
No documented EoL decision or review during admission	3* (7)	45 (82)
Family conference documented	30 (70)	6 (11)
Median bed days before death decision recorded (days)	3	NA

* In the patient deaths sample, two of the three patients with no documentation of EoL care were admitted to the palliative care unit where policy for admission includes that the patient is not for cardiopulmonary resuscitation

with a medical practitioner who they know and trust. As EoL discussion is ideally initiated before illness inhibits communication, the GP is central to this process.[16]

That primary care is well placed to facilitate advance care planning is generally supported.[4,9,11,17] Overcoming reluctance to talk about death and dying,[18] and initiating advance care planning provides an opportunity for the patient and those close to them to prepare for death and confirm EoL treatment preferences.

There are limitations to this study. It was confined to a single centre, and as a retrospective review of medical records, the results are dependent on the quality of documentation, which may not necessarily be a true reflection of any discussion. Only available records were reviewed although there is no reason why the absent records would cause bias in the findings. In addition, larger sample sizes would allow for the use of statistical analysis to confirm the validity of the findings. This study did not examine the prevalence of advance care planning discussion in primary care. Assuming such discussions are occurring, this study suggests that any decisions made are not effectively communicated to acute care and are not generally available in acute care unless disclosed by a competent patient.

Implications for general practice

The EoL discussions that dominated this study may have been necessary irrespective of whether or not there was an advance care plan. However, armed with an established relationship with the patient and knowledge of their health situation, the GP is best placed to initiate discussion concerning EoL care values and treatment preferences sooner rather than later. The GP can facilitate such decisions being available and honoured in acute care by strategies such as encouraging the patient to take a copy of their advance care plan with them if admitted to hospital and by suggesting that the patient provide a copy of their advance care plan to their person responsible.

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