



Retrospective audit of deaths in Canterbury District Health Board

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Abstract

Aims

To gather demographic data on deceased persons and assess their case notes for evidence of best practice in care of the dying, as established from available literature.

Methods

An audit tool was developed to assess deaths as part of a short-term research project for the purpose of collecting this data. The case notes of patients who had died in Christchurch Hospital, the Nurse Maude Hospice and two aged residential care (ARC) facilities in Christchurch were retrospectively reviewed between November and December 2015. Deaths were categorised as hospital or community (hospice and ARC) and 'expected' or 'unexpected'. The latter categorisation was made using a descriptive table that identifies illness characteristics that preceded the death.

Results

Hospital deaths were predominantly in older patients on general-medical wards. A significant difference was found between 'expected' and 'unexpected' deaths in hospital in terms of the number of quality indicators of dying that were identified. No significant difference was found between 'expected' deaths in hospital and community settings. Specific indicators that were less commonly documented in the clinical notes were 'discussion of the preferred place of death', 'spiritual needs', and 'after-death care'.

Conclusion

Based on the clinical documentation, it is possible for patients to have a 'good' death, regardless of location or background illness if physical, emotional, cultural, spiritual, and family/whānau needs are met. The audit, however, reveals aspects of care that are not well documented for dying patients, providing the opportunity for further education and standardisation of care.

Introduction

Ensuring that patients have the opportunity to die comfortably and well supported is an important priority throughout the health care system. Quality of death is not only about the person's final moments, but the ideals and preferences around the dying process in the last days, weeks, or months of life.^{1,2} This means taking into account the physical, emotional, cultural, and spiritual aspects of death³⁻⁶ for both the patient and their family/whānau.^{7,8}

In 1997, the Institute of Medicine defined a 'good death' as 'free from avoidable distress and suffering for patient, family, and caregivers, in general accord with the patient's and family's wishes, and reasonably consistent with clinical, cultural, and ethical standards'.⁹ This definition is now over 20 years old and contains terms that are subjective and difficult to measure, therefore it is not surprising that there are no international standards for delivery of care to optimise a good death for patients.^{8,10,11} The need for a set of robust measures of quality of death, however, is evident.^{10,12,13} One reason for the lack of international standards and definitions may relate to the nature of death itself. Studies cannot easily evaluate the person themselves as they are dying, and the person cannot of course be asked how they experienced their own death. The quality of death has to be analysed from surrogate sources and will inevitably be retrospective. Options include proxy interviews or questionnaires to ascertain the views of the patient's family/whānau, interviews or questionnaires of health care staff who provided care leading up to the time of death, and the analysis of case notes, looking for specific markers or determinants following the death. It is well known that opinions vary within the different proxy groups¹⁴ and while proxy interviews provide an insight into the family/whānau perspective, they may not always be accurate for the patient's wishes and needs.^{1,5,15,16} It is clear that all three options have their limitations.

Death is personal to the individual,¹⁵ therefore, defining exact outcomes and definitions of the physical, emotional, spiritual and cultural aspects is problematic.¹⁰ There are a number of factors that appear to be of particular importance. These include good symptom control, an

established doctor-patient relationship, adequate time to prepare for the end of life, and a sense of life completion.^{9,11,17-22} Most of the literature on death and dying has focused on cancer patients.²³ However, it is important that an understanding of the factors governing a good death are also developed for deaths from other causes. At present, whether the needs of cancer patients who are dying differs to those of non-cancer patients is unknown.^{24,25}

Established mechanisms for reviewing deaths within health care services centre on mortality and morbidity (M and M) review meetings. These tend to be focused on adverse events rather than a wider review of the holistic care provided.^{18,26} In the Oncology Department, Christchurch Hospital, Canterbury District Health Board (CDHB), it was recognised that M and M meetings were a good forum to review individual deaths, but no mechanism existed to systematically review all deaths.

The purpose of this study was to develop a robust process for retrospective evaluation of the case notes of deceased patients based on best practice, as established from available literature. Aspects of identified best practice were broken down to individual components termed 'quality indicators'. The primary outcome was to create a percentage score that reflected the number of quality indicators present for each death. Secondary outcomes were to compare scores by variables such as hospital department, location and type of death, as well as to identify individual quality indicators that occurred frequently or infrequently.

Methods

A retrospective audit of case notes for all deceased patients, from November 2015 to December 2015, from all wards of Christchurch Hospital and Ashburton Hospital was performed. There was a single auditor with a basic level of clinical knowledge. Christchurch Hospital is a 600-bed tertiary referral centre, serving a population of approximately 500,000. Ashburton hospital is a rural hospital also located within the CDHB.

An audit tool was created based on items identified from the literature that have been shown to be a marker of a good death.^{2,24,27-29} The tool included patient demographics, hospital information, and indicators for physical, spiritual, cultural and emotional aspects of death (examples in Table 1). A positive score was allocated if the notes documented that the item had been considered by the scribe in some way, rather than the presence or absence of a particular symptom. Each item had an equal weighting of one point. A final score was calculated based on the number of quality indicators per death, with the highest possible score being 34. The total score was also calculated as a percentage of the maximum possible score, with higher scores indicating that more of the quality indicators were present.

Each death was also categorised according to a pre-agreed definition (Figure 1), this did not affect the final score. These categories were grouped into 'expected' (categories a, b, and c) and 'unexpected' (categories d, e, f, and g) deaths. This categorisation was largely a reflection of whether or not the patient was assessed as having a progressive, life-limiting condition or frailty prior to death.

All hospital deaths were notified to investigators by mortuary staff during the study period, which was chosen due to availability of the auditors. Hospice deaths were notified by the hospice nurse manager and the deaths in the two ARC facilities were notified by the respective clinical managers. The audit tool was applied to the written and electronic clinical case notes of deceased patients in the hospital, and only the written case notes in the hospice and ARC facilities' audits on the hospital deaths were completed within 72 hours of death. In order to test the applicability of the tool to deaths in a community setting, the tool was modified to remove items only applicable to hospital-based care (e.g. admission to intensive care unit). Two ARC facilities in Christchurch and one hospice were also audited (Nurse Maude Hospice, Christchurch).

The ARC facilities were chosen for their large size and ease of access to deceased patient notes. As deaths are less frequent in these settings, notes from as early as July 2015 were included in order to obtain the most recent ten deaths from each.

Category	Examples of quality
Demographics	Age at death, date of hospital admission, date of death, sex, ethnicity, inadequate understanding of the English language, presence of hearing impairment or aphasia, lead doctor, place of death. Time taken to complete audit.
Physical	Presence or absence of pain, restlessness, delirium or agitation, respiratory distress, urinary or bowel symptoms, pressure area cares and mouth cares. Anticipatory prescribing for pain, dyspnoea, respiratory tract secretions, nausea and agitation, intravenous fluids and unnecessary medications ceased. Presence or absence of intensive care unit review, clinical emergency call, or Early Warning Score documented.
Spiritual	Documentation that spiritual needs identified.
Cultural	Documentation of holistic care that honours dignity and culture of the patient, own room, any communication or language barriers present.
Emotional	Documentation of discussion around fear of dying, preferred place of death and if this was adhered to.
After-death care	Documentation of after-death care of the patient, and bereavement care of family/whānau.
Communication	Documentation of medical assessment, diagnosis of dying, advance care plan, referral to palliative care team, Do Not Attempt CPR order completion, ceiling of care documentation, communication with family/whānau prior to or after death.

Table 1 Items included in the audit tool

To compare demographic data and overall percentage scores between the different health care settings, an unpaired two samples Wilcoxon test in R (Mann-Whitney-Wilcoxon) was used. The individual items were ranked in each setting to see which items showed high or low levels of documentation. Statistical analysis was performed using Microsoft Excel and R.

The Health and Disability Ethics Committee's approval was not required due to the retrospective nature of this audit.

Results

A total of 143 patient deaths were audited: 112 in hospital; and 31 in the community (ARC n=22, hospice n=9). A total of 25 unexpected deaths occurred in hospital. No unexpected deaths were recorded in community setting. The demographic data of the patients in each setting are presented in Table 2. As ethnicity was so variably reported, only New Zealand European/Pākehā and New Zealand Māori are included. No patients in the sample were in the 45-54 years age group and only seven patients (6%) under the age of 55 years died in hospital. In the community setting there were no deaths under the age of 55.

Table 3 shows the wards/services where hospital deaths occurred, and

- a) Anticipated death due to active, progressive, advanced disease^x
 - b) Patient has active, progressive, advanced disease^x or frailty but death occurred despite medical treatment aimed at recovery from acute episode OR death occurred following precipitous deterioration either in hospital or en route
 - c) Patient has active, progressive, advanced disease^x or frailty and condition most likely preventable, but medical treatment NOT initiated due to associated factors such as dementia, valid advanced directive etc.
 - d) Unexpected hospital death from acute illness (e.g. myocardial infarction, sepsis, stroke) with NO prior active, progressive, advanced disease^x
 - e) Unexpected community/ED death (e.g. out of hospital cardiac or respiratory arrest – previously medically stable)
 - f) Death due to trauma/MVA
 - g) Unexpected death from medical intervention, omission or error[#]
 - h) Uncharacterised due to lack of information
- ^x Otherwise referred to as terminal illness, amenable to palliative care
- [#] These cases are likely to be referred to the Coroner, who may or may not take jurisdiction

Figure 1 Categories of death
ED = Emergency Department. MVA = Motor Vehicle Accident

the mean, median and range of percentage scores for these services. Most deaths occurred on medical wards (n=58 or 41%), followed by the intensive care unit (ICU) (n=12 or 8%). Orthopaedic wards were also well represented in this audit (n=8 or 5%). Deaths in the Older Persons Health Department and Emergency Department (ED) were less frequent (n=4 or 3% and n=7 or 5% respectively). In the hospital setting, the percentage scores were higher in expected deaths than in unexpected deaths (percentage scores 55%, range=21-76% compared to 43%, range 15-71%, p<0.01). There was no significant difference in total scores between the hospital and community expected deaths (55%, range=21-76% compared to 57%, range=24-76%, p=0.52).

The highest and lowest scoring items in both the community and hospital settings were analysed. (Table 4 and Table 5). In the hospital expected deaths, the higher scoring items are associated with physical aspects of death, e.g. clinical emergency not being called. The low scoring items are associated with more spiritual or cultural aspects, e.g. patient's fear of dying.

	Hospital	Community
Number	112	31
Age, (years) ¹		
	<45	7
	45-54	0
	55-64	15
	65-74	23
	75-84	30
	>85	37
Mean age, (years)	74	77
Male, n (%)	55 (49)	15 (48)
New Zealand European/Pākehā, n	94	28
New Zealand Māori, n	6	1
Other ethnicity ² , n	40	11

Table 2 Demographics of audited cases

1. One age is unknown

2. Other ethnicities included Pacific island nations and other European countries. Where more than one ethnicity is recorded by an individual it has been counted under each category.

Location	Number (%)	Mean Score % (range %)
Medical (including Oncology)	58 (41)	59 (32-76)
ICU/CICU	12 (8)	44 (24-68)
Orthopaedics	8 (5)	44 (26-68)
ED	7 (5)	26 (15-46)
Surgical	6 (4)	47 (21-65)
Nephrology/Cardiology	5 (3)	50 (26-65)
Older Persons Health	4 (3)	50 (35-65)
Children	2 (1)	32 (24-41)
Ashburton Rural Hospital	10 (7)	56 (24-71)
Community	31 (22)	55 (28-79)

Table 3 Location and distribution of quality of death scores

ICU = Intensive Care Unit. CICU = Cardiac Intensive Care Unit.

ED = Emergency Department

	Expected	Unexpected
Top 5 items (%)	Presence or absence of discomfort or pain (97)	Medical assessment completed within 24 hours prior to death (84)
	Presence or absence of restlessness or agitation or delirium (89)	No evidence of a clinical emergency call (84)
	No evidence of a clinical emergency call (89)	No evidence of ICU outreach being contacted (80)
	Presence or absence of respiratory distress (87)	Presence or absence of respiratory distress (76)
	Completion of DNACPR form (86)	Meeting with family/whānau/support person/people (76)
Bottom 5 items (%)	Presence or absence of the patient's fears and concerns around dying addressed (17)	Acknowledgement of an Advanced care plan/Advanced Directive/Living Will in the notes (12)
	Documentation bereavement care given to the family/whānau/support people after patient has died (9)	Presence of Advanced care plan/Advanced Directive/Living Will in paper or electronic form (8)
	Documentation of the patient's preferred place of death (8)	Documentation of the patient's preferred place of death (4)
	Identification of the presence or absence of patient's spiritual needs (7)	Presence or absence of the patient's fears and concerns around dying addressed (4)
	Documentation that the patient's preferred place of death was adhered to (1)	Documentation that the patient's preferred place of death was adhered to (0)

Table 4 Hospital expected and unexpected death percentages of highest and lowest documented outcomes*.

* Percentages indicate proportion of cases where this item was scored as present

DNACPR = Do Not Attempt Cardiopulmonary Resuscitation

	Expected* Community
Top 5 items (%)	After-death care of the patient e.g. washing of the body (97)
	Presence or absence of restlessness or agitation or delirium (94)
	Anticipatory medications prescribed for pain and dyspnoea (90)
	Anticipatory medications prescribed for agitation (87)
	Presence or absence of discomfort or pain (84)
Bottom 5 items (%)	Documentation of patient's concerns and fears around dying (23)
	Presence of holistic care that honours dignity and culture (13)
	Documentation of ceiling of care (10)
	Documentation of the patient's preferred place of death (6)
	Documentation that the patient's preferred place of death was adhered to (3)

Table 5 Community death percentages of highest and lowest documented outcomes

• No unexpected deaths occurred in the community

Discussion

The aim of this study was to develop an effective process to retrospectively review deceased patients' case notes with the objective of reviewing the quality of their death. The tool functioned effectively and was able to provide a consistent means of measuring health professionals' documentation of physical, emotional, spiritual, cultural and family/whānau issues, which act as a surrogate marker of the quality of death. This study provides important demographic data about deaths in the CDHB. A significant proportion of deaths occurred in high acuity areas such as orthopaedic surgery or intensive care. There was marked variation between patients in the level of documentation prior to and after death. These findings indicate that comprehensive documentation about death is not yet being achieved and supports the systematic use of the audit tool in assessing quality of death.

Audit results were made available to each service/department to identify examples of excellent practice, as well as any deficiencies and gaps. The aim of this was to drive improvements via education, support and policy development. The experience of how people die lives on in their loved ones and in the staff who cared for them. This is why it is so important that care for dying patients is scrutinised closely – so that lessons can be learned and improvements made.

From using the tool, it was apparent that quality indicators relating to physical symptoms consistently score higher than those relating to emotional, cultural and spiritual items. This may be because physical symptoms are easier to identify and remedy than symptoms relating to spirituality and culture. The finding that physical symptoms are reported more is consistent with the literature.^{12,27}

A holistic approach to care at the end of life is important, as cultural and spiritual aspects can have a dramatic impact on end-of-life care.¹¹ For example, patients of Christianity, Judaism and other major religions differ markedly in their philosophy around end-of-life care.³⁰ Chinese culture suggests that mortality is discussed with a patient's family, and not the patient themselves, as this can cause the patient undue stress.³¹ Culture is not just related to ethnicity, as patients and health care workers also have their own culture. In a study looking at which aspects are important in end-of-life care, patients rated control of physical symptoms highly with mental awareness a close second, whereas the doctors saw the treatment of physical symptoms far superior to mental awareness.³² Another study found that patients were more likely than family members to rate religious or spiritual beliefs as an important contributor to a good death.¹¹ This can dictate who makes decisions for the patient, whether treatment efficacy can be discussed, and specific traditions around the dying process.³⁰ These different cultural and spiritual experiences may help to explain why specific quality indicators surrounding dying are not consistently addressed.¹⁸ A higher level of cultural and spiritual understanding (and possibly education) is required for health care staff in order to provide the best care possible.

In the hospital setting, 41% of deaths occurred on medical wards and only 3% of deaths occurred within the Older Persons Health department. This finding of a low percentage of patients dying in geriatric wards may reflect that most were receiving rehabilitation and that patients who are relatively stable medically are being admitted for rehabilitation in the CDHB.

In the hospital setting, expected deaths were associated with a higher quality of death compared to unexpected deaths. This is unsurprising, since in an expected death patients have more time to prepare for death and so can say goodbye to loved ones, have their symptoms well controlled and live their remaining days in comfort.^{7,20} Compared to a patient who, for example, comes into the ED after a trauma where it is uncertain if they will live, the focus is on survival as opposed to having religious, emotional, physical, and cultural needs met. This does not mean that a good death is unachievable in these situations as some individual

scores were high, meaning that despite the suddenness of the death, it is still possible to focus on symptom management, communication, and family support.

There was no significant difference in expected deaths between hospital and community settings, suggesting that quality of death was similar in the two groups. This result suggests that care provided in hospital is not dissimilar to care received in the community at the end of life. However, this result needs to be interpreted with caution, as ARC and hospice were analysed together due to low numbers. Hospice patients had consistently higher scores than ARC, whose scores were more varied. Future studies are needed to examine the differences between the three groups: hospice, ARC and hospital.

Low scoring items indicate areas that may need improvement. These were advance care planning (ACP) and areas around the spiritual and emotional aspects of death. ACP is a relatively new initiative (within the last ten years).^{33,34} ACP has been a focus in the CDHB for the last three years. ACP allows patients to express their wishes around death and dying weeks, months or years beforehand.^{33,34} These plans often address some of the low-scoring emotional and spiritual aspects measured in this audit tool and increased use of these plans may improve performance in this important area and improve several indicators of a good death. Bereavement care of family/whānau is also a low scoring item. At present, there is no mechanism in Christchurch Hospital to document care provided after the patient has died, either electronically or on paper. The introduction of such a mechanism could be of value to document care provided to the patient's family/whānau after death.

One explanation for low scores in quality of death indicators is physician mindset. The focus of health care professionals is geared towards keeping patients alive, and hence diagnosing dying can make health care professionals feel inadequate²³ or that they have failed.² However, the act of diagnosing dying can allow initiation and assessment of some of the emotional, cultural, and physical cares of the patient and family/whānau,^{7,15,35} and opens a forum for communication between patients, families and health care professionals. Diagnosing dying provides the best opportunity for a good death.²³

Limitations

The results of this study should be considered in the context of several limitations. Firstly, aspects of the audit tool itself have limitations. As part of developing the audit tool, the tool was refined during data collection. As a result, some of the information from the beginning of the process might be recorded differently to data that was collected in later versions. Furthermore, the tool requires intra- and inter-observer variability testing to ensure it is robust and repeatable. Additionally, the tool differentiates between expected and unexpected deaths based on the patient's prior medical condition and the events leading to death. This is a subjective distinction and is particularly problematic when judged retrospectively (after the patient has died).

Secondly, the retrospective nature of the study is a limitation. Assessing the quality of dying at the time it is happening is not feasible logistically and could be deemed as an inappropriate intrusion. However, retrospective reviews can still provide useful information. In this case, this study highlighted that documentation of care surrounding dying needs improvement.

Thirdly, we interpreted the lack of documentation about quality indicators as meaning they did not occur, but this is not necessarily the case. Nonetheless, the level of documentation in itself is an important outcome measure, since it enhances the quality care by serving as a communication tool between the different health care professionals caring for that individual.

Fourthly, although theoretically the most accurate source of data in studies on dying, patient interviews are difficult to conduct and not always appropriate.¹⁶ In some cases, this study took into account the direct patient perspective with verbatim statements in notes, however this was inconsistent. Moreover, it did not take into account family/whānau experiences or health care professionals' opinions on the patients' qualities of death. Collection of this information would allow a more three-dimensional assessment on the quality of an individual death.

Despite the limitations, it has been possible to demonstrate that systematic analysis of dying is possible from the clinical records and that valuable results can be obtained. It provides an excellent platform for further study.

Conclusions

This study found that expected deaths generally had higher quality-of-death scores than the unexpected deaths, according to the clinical documentation. Physical symptoms are better documented than emotional, cultural and spiritual aspects of care. The recording of family/whānau communication and level of family/whānau support varied to a greater extent, including after the time of death. However, it is not clear if these observations reflect practices that are not being done, or simply not being documented.

The audit tool tested in this study can be used to evaluate quality indicators of death and identify areas where improvements may be made. Systematic application of this audit tool across the CDHB and potentially other organisations (such as ARC facilities, other district health boards or hospices) would facilitate the distribution of resources, including education provision and specialist palliative care support. Resources could specifically target low-scoring locations (such as wards where deaths occur infrequently, or areas where there are a high number of sudden or precipitous deaths, such as EDs), low scoring areas of care provision (such as recognising dying and spiritual care) and support further improvements in high-scoring areas. Future research should be targeted towards a more inclusive review of quality of death that correlates family/whānau/caregiver and health care professional's opinions with retrospective case note review.

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Acknowledgements

The authors would like to thank Dr Carol Douglas, Palliative Care Physician, Royal Brisbane Hospital, Queensland, Australia, for sharing the table used locally for categorisation of all hospital deaths as part of their quality review process.

Funding

University of Otago Christchurch Summer Studentship Programme

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