

DYING FOR ATTENTION: PALLIATIVE CARE IN THE ACUTE SETTING

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ABSTRACT

Background:

Palliative care has emerged as a specialist discipline in the past 25 years. However in relation to acute hospitals, a sense exists that patients who are receiving end of life care may not experience support which fully reflects appropriate palliative care management.

Objective:

This study aimed to analyse the end of life care received by patients in the acute wards of a busy teaching hospital.

Design:

Retrospective analysis using multiple methods including: case note auditing and interviews of key staff was used to determine the quality of end of life support provided to an opportunistic sample of patients who died in acute care wards.

Setting:

The research site is a 250 bed teaching hospital in South Australia.

Subjects:

A medical record audit using an opportunistic sample of 20 recently deceased patients from acute wards was used. For each patient, interviews were also conducted with two nurses (n=40) selected on the basis of having a major care involvement.

Main Outcome:

A range of strategies for enhancing the end of life care for patients in acute wards were determined, including support for application of a Palliative Care Advanced Disease Pathway.

Results:

The lack of appropriate assessment and documentation indicates that major opportunities for enhanced service provision exist both in relation to physical care and even more significantly in relation to psychosocial and spiritual care.

Conclusions:

The end of life care provided for patients reviewed in this study indicates a far from ideal situation in the acute hospital wards of the research setting. An eagerness from the nurse participants in the study for tools and further support in their practice was noted and augurs well for future developments within the research site.

INTRODUCTION

This paper describes a retrospective study of the end of life care provided to 20 patients who died in acute wards. The research site is a 250 bed teaching hospital with a focus on service provision for older people. The aims of the project were to:

- analyse the end of life care received by patients in the acute wards of the hospital;
- identify best care principles and relate these to the actual care provision;
- recommend learning opportunities and strategies for nurses working in the acute wards of the hospital; and
- identify whether a need exists for a Palliative Care Advanced Disease Pathway (PCADP) and identify other strategies to enhance nursing palliative care in the acute setting.

Major findings around nursing assessment, the nurses' perceptions of the care provided, communication and

decision making, and the psychosocial and spiritual aspects of care are discussed and recommendations for the way forward are highlighted.

LITERATURE REVIEW

In South Australia, 41% of deaths occur in public hospitals: 26% in non-designated palliative care beds and 36% in a hospice or palliative care designated bed in a public hospital (DHS 2001). There have been few comprehensive studies undertaken to explore the outcomes of the range of palliative services provided in various settings.

The care of dying patients in the acute general hospital setting – international research

International studies in relation to dying in the acute care setting have persistently indicated that there are problems with poor symptom control and inadequate nursing care (Mills, Davies and Macrae 1994). Administrative data confirms that interventions and investigations often continue up until death (Earle, Elyse et al 2003). Poor communication, in particular clear and honest communication between health professionals and the patient, is still a key issue (Curtis, Weinrich et al 2001; Carline, Curtis et al 2003). Many nurses never discuss hospice care with their patients and others avoid discussing prognosis (Bradley, Cherlin et al 2001).

Australian research

Australian data has been sparse on this topic. An early study in South Australia (Ashby, Maddocks et al 1991) found poor levels of terminal care in public hospitals. Relatives also indicated that doctors were found to be inaccessible and uncaring (Wakefield and Ashby 1992). In addition, 25% of patients had uncontrolled severe pain, 57% of hospitals did not have bereavement care and many respondents were dissatisfied with the overall standard of care. These findings indicated that public hospitals were considered by the majority of respondents to be providing unsatisfactory terminal care.

More recently Pincombe et al (1998) examined the care of 20 patients who died in two acute general hospitals in South Australia. Findings indicated that the overwhelming amount of care offered to dying patients by health professionals was associated with routine and technological care, and that the presence or absence of family and their activities and attitudes significantly influenced the quality of care received by the patient. It was found that nurses experience considerable stress when patients are dying in an acute care setting because of competing demands on their time and/or their lack of experience and/or the absence of positive role models. Improved education in the palliative approach for all staff was recommended. Pincombe et al (1998) concluded that the principles of palliative care are yet to be fully incorporated into the acute care setting.

The Pincombe et al (1998) findings are further reinforced by Middlewood et al (2001), who described patterns of medical and nursing practice for patients dying of oncological and haematological malignancies in a Canberra Hospital. They found that although 88 out of 100 patients had 'do not resuscitate' orders, 48 had been documented less than two days prior to death.

The overall results confirm that the principles of palliative care had not been adequately incorporated into the acute care setting.

RESEARCH METHODS

Study design

The study sought to retrospectively analyse the end of life care provided to 20 patients who died in acute wards of the hospital. Multiple methods were used. A case note audit tool was developed utilising the Beth Israel (1999) palliative care advanced disease pathway framework (PCADP). This included a review of documentation in relation to the major aspects of comfort care including nursing assessment of physical, psychosocial and spiritual care.

Information from the medical record audit related to whether a comprehensive nursing assessment occurred, whether the appropriate nursing interventions were implemented as a consequence of the assessments, and whether the nurses documented the outcomes of their interventions and undertook appropriate modifications to nursing care accordingly.

This data was supplemented by data from interviews with two nurses identified as having a major care involvement with each patient. A staff interview tool was used which was also developed utilising the Beth Israel (1999) framework for their PCADP. Nurses were interviewed within one week of the patient's death to enhance recall of the specific episode of care.

Sampling

The selection of medical records to be retrospectively audited was through opportunistic, random sampling. The medical records selected were those of the most recently deceased patients from an acute medical or surgical ward at the time the nurse research assistant was in a position to undertake the next audit. Medical records were excluded if the patient had died unexpectedly without a recognised terminal phase. In total, 20 medical records were audited. Interview selection was undertaken through case note audit identifying two nurses who were most involved with the patient's care in the last days of life.

Ethical considerations

Institutional ethics approval was gained. An information sheet identifying the nature and rationale for the study was provided to all nurses approached for interview consent. Standard statements identifying that participation was voluntary and that participants could withdraw at any stage were included. There were no

difficulties in gaining consent, with only one nurse declining to participate out of the 40 nurses approached.

Data analysis

Quantitative data was entered into an Access database for storage and manipulation. Qualitative data was analysed on a case by case approach to determine specific themes within the categories in which data were sought. Themes were independently drawn out by two of the researchers and individually checked by the investigating team. Cross sectional analysis was then used to cluster and label core themes that were interrelated and repeated between cases.

RESULTS AND DISCUSSION

Patient demographics

All patients had died within one and six days prior to data collection. There were 10 male and 10 female deceased patients. Length of hospital stay varied between 1 and 80 days (average 25.7 days). The patients included in the study were all elderly, which reflects the demographics of the hospital. The patients had a range of medical conditions including malignancies, cardiac, and respiratory disorders.

Nurse demographics

The nurses (n=40) were aged between 20 and 55 years, with 87.5% being 36 years and over. The age demographic of the nurses reflects the average age of nurses at the hospital (43 years). Nursing experience varied from 1 to 27 years with 60% having more than 11 years nursing experience. Palliative knowledge was self perceived to be 'below average' (2), 'average' (16), 'better than average' (20) and 'excellent' (2), with 95% rating palliative knowledge as average or better. Conversely, 65% rated their confidence in delivery of palliative care as 'reasonable' and only 27.5% felt 'very confident' in their delivery of palliative care. With regard to qualifications, 19 out of the 40 nurses held a Bachelor of Nursing, while 21 out of the 40 were hospital trained registered nurses. The remaining five nurses interviewed were enrolled nurses (12 months formal education).

There was very little difference in the knowledge and confidence rating between hospital trained nurses and those with a nursing degree. Both nurses who rated their knowledge as excellent were hospital trained.

MAJOR FINDINGS

The major findings can be grouped according to four specific areas of care provision:

- nursing assessment,
- nurses' perceptions of care provided,
- communication and decision-making, and
- psychosocial and spiritual aspects of care.

Nursing assessment

The nursing care plans at the time of death were reviewed for each patient. Of these, 13 were considered to match identified need but in seven cases the frequency of observations was considered inappropriate. The dimensions of care that were pre-determined included: physical, psychological, social and spiritual aspects of care. Review of the medical records revealed that for 18 patients the physical aspects were documented, however, psychological and social aspects were only documented for 6 of the 20 patients and only one patient had any documentation recognising spiritual needs.

For each patient the three main symptoms were identified in the medical records and correlated through the interview process. In 40% of cases the major symptoms most frequently documented were not the same as those identified by the nurses during the interview process. It was concluded that the documentation of symptoms was rarely adequate or comprehensive enough to influence treatment decisions.

Nurses' perceptions of care provided

The nurses were asked to rank their general impressions on the patient care provided. There were four criteria ranging from 'none of needs met' to 'exceptional care given'. The analysis revealed that 47.5% felt that some of the needs were met, 45% felt that all the needs were met and 7.5% reported the care as being exceptional.

The nurses were asked to comment on the usefulness of a palliative care pathway and specific education to enhance their ability to provide end of life care. All but one respondent felt a pathway would be useful. With regard to education, the majority of nurses identified the need for further continuing education in relation to palliative care. The most frequently requested subjects included pain and symptom management, dealing with families, communication skills and assessment/recognition of disease progression and the terminal phase.

Communication and decision making

In relation to treatment choices, nurses indicated that eight of the 20 patients were involved in decision making in relation to their care. The remainder of patients were classified as 'unable to comment' for a range of reasons including being unresponsive, unable to communicate or that the patient's family was in conflict or was unavailable. It appeared that the issue of death was rarely discussed, even if raised by the patient.

No evidence could be found of advance directives in the form of 'living wills'. Not for resuscitation (NFR) orders were recorded for all patients, but it was not always clear whether patients or their families had been involved in this decision.

In 11 cases the terminal phase was recognised by the nurse and documented. Thirteen families were notified of

impending death between 25 minutes and 48 hours prior to the event. In 10 cases family members were present at the time of death.

The documentation around family involvement was very poor, with communication and concerns only surfacing in the terminal phase. There were no formal multidisciplinary conferences between health professionals and families although in six cases there was documentation of families expressing distress, anxiety, anger or concern about the patient's care or prognosis.

A theme of powerlessness emerged in relation to the nurses' concerns about poor communication between nursing and medical staff with regard to treatment choices for patients. Difficulties in accessing doctors after hours to meet with distressed family members were also reported by the nurses.

Psychosocial and spiritual aspects of care

There was little documentation relating to the management of non-physical dimensions, despite significant ongoing issues in these areas for some patients and families. Documentation of physical symptoms occurred in all patient medical records ($n=20$), whereas psychological symptoms or issues were only recorded in six (30%), social in nine (45%) and spiritual in one (5%). For seven patients (35%), the care of physical needs was the only dimension reported. In four sets of medical records both physical and social issues were mentioned; physical and psychological issues were noted in two others. In four cases (20%) physical, social and psychological dimensions were documented in some form. In only one patient's medical record were the four dimensions: physical, social, psychological and spiritual, all documented.

Of the 40 nurses interviewed, 38 were able to identify the 'significant others' of the patients for whom they cared. Documentation of family involvement occurred in 18 medical records. This was largely restricted to noting visits, however in two cases the presence of particularly supportive family members was clearly stated. Discussions with family were also documented, as were, occasionally, family members' concerns. Interactions between the patient and family were rarely mentioned. Insights into family dynamics are therefore missing from most of the patient records, although widely recognised in health care as impacting on health outcomes, including a 'good death'.

Of the research cohort, none of the patients had cultural issues which appeared to be significant. There was no mention of culture in either interviews or medical records, apart from one case note mention of a patient's Dutch origins. While it was noted by the research team that had there been cultural issues, there was nowhere in the formal case note assessment tools to document these concerns.

Similarly, the formal tools contain no prompts for documentation of spiritual issues beyond a line in the

hospital admission form on which to note a patient's religious denomination. The only patient case note entry mentioning the spiritual dimension was limited to a notation of a visit by a pastor.

DISCUSSION

The nurses' knowledge of palliative care self-ratings did not correlate with their confidence or their ability to provide expert palliative nursing support or with the inadequacies in care identified. There was some evidence of appropriate care planning for patients, but this was primarily in relation to physical needs. Very poor correlation existed between documented identification of symptoms and the verbal feedback provided by the nurses interviewed. The inevitable result of poor assessment and planning was: inconsistent and ad hoc symptom management; and inadequacies in evaluation and modification of care planning.

Of further concern was the minimal recognition of the psychological, social and spiritual needs of patients and their families. Communication between nurses and patients and their families was poorly demonstrated. Documentation of fear, anger or distress was made, but the issues appeared to be unresolved. There were no formal family conferences recorded.

In nine cases, death was not recognised as imminent in the medical record and in five cases no signs or symptoms of the terminal stage were documented. Seven families were not informed that death was imminent and therefore missed the opportunity to be with their family member. It is difficult to assume there were no signs of the terminal phase present. It would seem that clinical staff were focussed on carrying out treatment rather than noting deterioration and spending time identifying and managing patient and family concerns.

Given the study was a retrospective review it is not possible to identify how these discrepancies and inadequacies impacted on patients, but it would be reasonable to predict that failure of documented identification of these needs led to omissions in care. These issues suggest a shortfall in palliative education and an inappropriateness of the acute setting to providing quality palliative care.

CONCLUSIONS

It was apparent from the study that nurses at the research site had a strong desire to provide quality palliative care to patients. However the lack of appropriate palliative assessment and documentation, particularly for patients who had a non-malignant life-limiting disease, indicated that in this study care provision could have been enhanced.

Furthermore, while concerns about the limitation of care provided were expressed by the nurses, there was limited focus in relation to the psychological, social and spiritual needs of the patients.

Nurses indicated that better care could be provided with increased resources, although it was not clear how these resources would be applied to enhance practice. Limitations in knowledge and expertise in relation to palliative care from the clinical treating teams were major factors which affected patient care, according to the nurses interviewed.

The nurses indicated strong support for the application of a resource such as a Palliative Care Advanced Disease Pathway for use in the acute wards of the hospital. They also indicated a range of areas where further education would be valued. Three major recommendations were developed:

1. Increase liaison between palliative care services and acute care settings, including the development of 'link nurse' positions.
2. Provide continuing education in palliative care, particularly in relation to the non-physical needs of patients requiring end of life support.
3. Develop comprehensive palliative care protocols including a standardised practical tool for the identification of holistic care needs for acute care facilities.

It was noted that a range of effective care was provided to the patients reviewed, particularly in relation to the commitment of the nurses, and it is easy to overlook this in the face of the significant discrepancies between ideal care and the care provided. Nurses also demonstrated a willingness to receive support and a strong desire to participate in identifying how this support might be provided. It is anticipated that further work in this setting will be embraced by the nurses practising in the acute wards and it is noted that the organisation is receptive to change. These factors augur well for fundamental changes

to nursing practices, building on the commitment and expertise already existing in the hospital and on evidence developing as international best practice.

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