Challenges to end of life care in the acute hospital setting

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Background: Research exploring patients’ care and treatment preferences at the end of life (EOL) suggests they prefer comfort more than life-extension, wish to participate in decision-making, and wish to die at home. Despite these preferences, the place of death for many patients is the acute hospital, where EOL interventions are reported to be ineffectively invasive and aggressive. Aim: This paper discusses the challenges to appropriate EOL care in acute hospitals in the UK, highlighting how this setting contributes to the patients’ and families’ care and treatment requirements being excluded from decision-making. Methods: Twenty-nine cancer nurse specialists from five hospitals participated in a grounded theory study, using observation and semi-structured interviews. Data were collected and analysed concurrently using the constant comparative method. Results: EOL interventions in the acute setting were driven by a preoccupation with treatment, routine practice and negative perceptions of palliative care. All these factors shaped clinical decision-making and prevented patients and their families from fully participating in clinical decision-making at the EOL. Palliative Medicine 2006; 20: 611–615

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Introduction

In recent years, interventions towards the end of life (EOL), and patients’ concerns and preferences regarding EOL treatment and care, have come under the scrutiny of researchers.1–3 This research reflects, not only western health care’s increasing concern with the escalation of health care costs, but also a preoccupation with patient autonomy and choice. In the UK, a central and consistent characteristic of health care policy in the last decade is the commitment to improve patients’ experiences of health care. Policy directives now advocate patient-centred rather than professionally driven care: this has resulted in the inexorable drive to implement strategies to increase and improve patient information, choice and participation in clinical decision-making at all stages of a disease trajectory.6–10

In view of the ethical challenges involved in exploring patients’ perspectives and preferences about EOL care, research focusing on these issues is relatively sparse. However, there is evidence to suggest that as death approaches, many patients prefer comfort measures over life-extension,4,5 wish to retain control of their life and participate in EOL decision-making.5,10 In addition, it appears that many patients would prefer to die at home.11,12

Despite home being the preferred place of death, in the UK only about 20% of patients achieve their wish.12 There are a number of reasons for this including inadequate symptom control, rapid and sometimes unexpected deterioration, insufficient support from community services and carers’ physical and emotional exhaustion.13,14 As a result, the acute hospital is often the setting where patients die in the UK.15,16 However, it seems that in this environment, interventions at the EOL may continue to be invasive and aggressive,17,18 and, as such, they do not always reflect patients’ preferences, or ‘good’ EOL care, which prioritizes effective symptom management and attends to the psychological concerns of the dying patient and family.3,19,20

The need to improve EOL care for cancer patients was a major force behind the development of palliative care services in the UK in the 1960s.21 Although palliative care originated and continues to exist outside mainstream health care, the last two decades have seen an increase in the number of professionals involved in providing supportive and palliative care to cancer patients in the acute hospital sector in the UK.22 Despite the increased longevity of people with cancer, improving EOL care continues to be an important aspect of the role of hospital-based supportive/palliative care professionals.

This paper draws on data from a qualitative study, that set out to explore the work of tumour-specific and palliative care clinical nurse specialists (CNSs) in the acute hospital setting. The paper focuses on data relating to patients in the last stages of life, and explores the challenges faced by patients, their families and professionals in delivering EOL care in the acute care setting.
The paper also highlights how the acute environment contributes to the patient’s and family’s preferences for care and treatment being excluded from the decision-making arena.

Method

The study used a grounded theory approach to develop insight into the work of cancer CNSs. Grounded theory is a useful method to use when little is known about a topic, when the purpose is to uncover the problems faced by participants within a particular context and how these problems are managed. In grounded theory, researchers aim to enter the field with few preconceived ideas about what will be found and endeavour to be open to events around them.

Participants

Following approval from Local Research Ethics Committees (LREC), participants were selected according to the principles of purposive and theoretical sampling and consisted of 29 CNSs from five hospital Trusts. Due to the recent expansion of nurses holding some form of specialist role in cancer care, lack of regulation and consensus about specialist nursing and specialist nurse titles, broad eligibility criteria were used to ensure that valuable informants would not be excluded. Eligible CNSs were hospital-based registered nurses, whose roles appeared to involve a high level of expertise within the field of cancer and palliative care, and whose role description included providing supportive/palliative care. Participants included:

- Three nurse practitioners
- Two research nurses
- Eleven tumour-specific CNSs
- Nine palliative care CNSs
- Four CNSs with combined tumour-specific and palliative care roles

Data collection

Data collection involved 135 hours of observation followed by semi-structured interviews. Some CNSs agreed to both observation and interview, resulting in observation with 15 CNSs and interviews with 17 CNSs. Observation took place in hospital outpatient and inpatient areas and included observing 73 CNS–patient interactions and numerous professional interactions. Patients were at various stages of the disease process, from those recently diagnosed with cancer, to those who were in the final stage of their illness.

The majority of interviews took place following the observation phase of the study. The interviews were tape recorded and lasted between 30 and 90 minutes. Observations and subsequent interviews became more structured as the study progressed, in order to explore CNSs’ concerns in detail and focused on:

- The nature of the CNSs role
- Access to patients
- Team members’ attitudes towards palliative care
- Facilitators and barriers to providing palliative care including EOL care.

Analysis

Fieldnotes from observation and transcribed interviews were thematically content analysed to identify a core category and related sub-categories using the constant comparative method used in grounded theory. The qualitative data analysis package, NVivo, was used to facilitate data management and analysis. Emerging categories were reviewed by KL and preliminary findings discussed with study participants who were able to attend a feedback session prior to compiling the final report.

Findings

Prioritization of treatment

One of the most significant challenges to providing appropriate care towards the EOL was staff’s preoccupation with treatment. Professional interventions were driven and overshadowed by treatment concerns. Significantly, CNSs reported there was minimal discussion, either within teams or with patients, about the overall aim and rationale of treatment:

I deal with haematology patients as well, and the perception there is that it’s treatment, treatment, treatment, right until, sometimes they don’t actually stop, people die having active treatments, when maybe somebody should have at some point said “Well look, where are we going?” (Interview: palliative care CNS)

The continuation of cancer treatment, even when patients were apparently dying, reflects the status of treatment in the acute hospital setting and also suggests that professional actions are influenced by what is routine and normal practice in any particular context. However, for CNSs, compliance with routine practice was a source of considerable frustration and contradictory to their beliefs about dying well, where comfort and control of symptoms take precedence.

A lot of my work is in the surgical area, and thoughts are very surgically-moulded, so for example things like intravenous fluids, at the EOL, three or four litres a day, and they’re actually prompting symptoms such as ascites and fluid overload and breathlessness, because their thoughts are still post-operatively rather than in EOL situations. (Interview: palliative care CNS)
Furthermore, palliative care was not always seen in a positive light. Instead, for professionals geared to meeting the demands of treatment, there was a perception that palliative care was ‘giving up’ on the patient when there was still much that could be done:

Rather than palliative care being a good thing, it’s actually seen in a very negative way and therefore kept at a distance. If the language of palliative care is difficult it might be fair to assume that the language of treatment is quite the opposite perhaps pro-active and positive, there is more to be done, there is more to be given. It’s still very much this separate camp – them and us camps. (Interview: palliative care CNS)

Prioritizing treatment and routine care also appeared to prevent attention to symptom management and discussion of patients’ views and preferences about their treatment and care, even when there was opportunity to do so due to the patient’s expected deterioration:

We went to see an elderly lady who had metastatic oesophageal cancer and bowel obstruction. She had been in hospital for about a week, was aware she was dying and had put her affairs in order. She told the CNS she wanted to die at home, but ward staff had not explored the practicalities of this or other options for care. The patient was still nil by mouth, subcutaneous fluids were being given and analgesia prescribed when necessary rather than regularly. (Observation fieldnotes: tumour-specific/palliative care CNS)

Although, in this case, the CNS had been able elicit the patient’s preferences, it was too late to for these to be acted on and the patient died a few days later.

Critical junctures

For some patients, the illness course appears unpredictable. Strauss et al.,26 describe how the trajectory of a serious illness is usually punctuated by critical junctures – points where current treatment could be evaluated in relation to changes in the patient’s condition. However, critical junctures were not always recognized as opportunities to review and reset the treatment plan to one more appropriate to the patient’s deterioration or explore patients’ or families’ preferences.

A patient with lung cancer was admitted and had surgery for a suspected space-occupying lesion but it turned out she had brain metastases. The nurses were still continuing to do neuro-obs, and there was a drain in the lady’s head. The daughter was absolutely frantic you know, “is she dying?” She was vomiting and she had headaches and you know her treatment was very medicalized really. The family, they didn’t want treatment to continue and wanted to get her off this really busy acute ward where no-one spent any time with them. (Interview: palliative care CNS)

Ethical challenges

Recognition of critical junctures did not necessarily promote easier decision-making. Instead health professionals sometimes seemed unsure about the best course of action, especially when patients were too ill to participate in decision-making and their views and preferences about care in the context of advancing disease had not been explored previously. While critical junctures provide opportunities to review current treatment plans, they also raise complex and uncomfortable ethical questions about what a patient’s deteriorating condition represents and whether it should be treated. Given the challenges of accurately diagnosing dying, the availability of an increasing array of treatments, and rising public expectations of health care, how professionals respond to these questions has important implications for patients. Some of these issues are highlighted in the following interview extract, where a CNS describes how she and the consultant differed in their perception of a situation concerning a very ill patient with dysphagia, and the most ethical course of action:

The consultant felt as though he couldn’t let her die in that way, so I just said I thought she was dying, and it isn’t pleasant having a feeding tube put in, they don’t always work, there are complications and the risk of having all that for the outcome, I didn’t feel that it was justified. He could understand where I was coming from and it did make him think about it, but he still was saying well you know we should give it a go. (Interview: palliative care CNS)

Even when patients are capable of expressing their wishes, it appears that the treatment ethos of the acute setting may contribute to a paternalistic professional stance, in which the views of certain categories of patients may be overlooked and, therefore, excluded from the decision-making process:

We went to see an elderly man admitted (not for the first time) with bleeding oesophageal varices. The patient looked very ill and frail: he had also been diagnosed with bladder cancer three years earlier but had refused treatment. In the medical notes, a treatment plan involving further investigations and surgery for the varices had been documented, but according to nursing staff, the patient just wanted to return home where he lived with his brother. The CNS talked to the patient about the proposed surgery: he was very sure he did not want any treatment, that he thought he was dying but had to die of something, and would rather spend his remaining time at home. When the CNS discussed his case with the senior doctor, she said she believed the patient had been mismanaged in the past and that the proposed surgery was essential. The CNS pointed out that the patient was very clear about what
he wanted and if he was aged 25 and mobile, he would simply discharge himself. While the doctor accepted this, she was also keen to pursue the banding to prevent further bleeding. (Observation fieldnotes: palliative care CNS)

Discussion

Inadequacies of an acute model of care

Twenty years ago, Strauss et al.,26 highlighted that hospital systems were becoming reliant on technologically driven and specialist services dedicated to and pre-occupied by the diagnosis, treatment and cure of acute illness. However, as the authors pointed out, the main users of hospital services are those suffering and ultimately dying from chronic disease, a category which could now include many cancer patients, due to the impact of treatment on longevity without the prospect of cure.27 Given the prevalence of chronic disease, it is unsurprising that there has been much debate in the literature about the shortcomings of acute care in meeting the needs of those whose disease is progressing or who are dying.1,2,28,29 While patients living with chronic disease may require treatment intermittently for acute episodes of illness, professionals should also remember that an acute episode occurs against a backdrop of ongoing and often advancing disease and may, in fact, represent a terminal event. Caring for patients in these circumstances requires a heightened sensitivity to the medical and ethical implications of treatment,30 and the courage to break from, when appropriate, treatment dominated routine. However, despite technical advances to aid the diagnosis and treatment of disease, technology has little to offer with regard to the accurate prediction of prognosis or diagnosis of dying,31 making clinical decision-making in advancing disease riddled with subjectivity and uncertainty. In the context of progressing disease, there is also professional reluctance to discuss alternative interventions with patients, families or within the team.18,32 It is, therefore, unsurprising that patients may receive treatment and care that is standard for the particular illness episode. This not only avoids the uncomfortable issue of uncertainty, but also removes the need to engage in the emotionally charged work of discussing withholding or withdrawing treatment.33

Initiatives to improve EOL care in the UK

Recent years have witnessed several initiatives designed to improve EOL care. The widespread introduction of an integrated care pathway for the dying,19,34 provides a structure to enable the principles of best hospice practice to be implemented in the acute environment. The pathway is designed to counterbalance the current inadequacies of EOL care in the acute hospital setting.35 However, in order for the pathway to be instigated, professionals responsible for the patient's care need to agree that the patient is dying and that further treatment is futile. The need for professional consensus could be seen as a potential stumbling block to the realization of appropriate EOL care. However, it should also promote open dialogue inter-professionally, between professionals and patients/families,35,36 and ensure that morally valid perspectives, other than patients’ medical interests, are brought into the decision-making arena.

More recently, UK health care policy,9,10,14 seems to suggest that the key to better decision-making lies in providing patient information and encouraging patient involvement at all stages of a disease trajectory. While promoting patient–professional collaboration in decision-making seems a straightforward solution, there are several issues that need to be acknowledged and addressed with regard to EOL care. Exploring patients’ preferences would need to take place earlier in the disease course, as patients are often too ill to participate in decisions at the terminal stage. Indeed, in view of the introduction of the Mental Capacity Act,37 professionals involved in providing EOL care may find that advanced care planning will become obligatory. But planning care in advance can be problematic. Evidence suggests that patients as well as professionals may prefer to avoid such discussions, feeling psychologically unprepared to contemplate their preferences in the light of potential EOL events.38 There are also concerns about the validity and reliability of advanced care plans. In addition, Clark et al.,5 note that patient choice at the EOL is negotiated in the context of the inequalities of the professional–patient relationship, the ‘powerful framework of medicine’ (p. 37) and influenced by the organizational culture of the institution where EOL care takes place. Therefore, it cannot be assumed that the choices patients make are a true reflection of their autonomous preferences. Despite these concerns, the sensitive application of strategies to facilitate patient choice and opportunities to approach EOL care proactively should be welcomed. It remains to be seen if these initiatives will be sufficient to secure the ‘good death’ advocated by palliative care philosophy, but so often missing in settings permeated by a culture of cure.5,39

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References


