

The care of dying people in nursing homes and intensive care units: a qualitative mixed-methods study

Elizabeth Perkins,¹ Maureen Gambles,²
Rachel Houten,³ Sheila Harper,² Alan Haycox,³
Terri O'Brien,² Sarah Richards,³ Hong Chen,²
Kate Nolan² and John E Ellershaw^{2*}

¹Health and Community Care Research Unit, Institute of Psychology,
Health and Society, University of Liverpool, Liverpool, UK

²Marie Curie Palliative Care Institute Liverpool, Institute of Translational
Medicine, University of Liverpool, Liverpool, UK

³Management School, University of Liverpool, Liverpool, UK

*Corresponding author

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Disclaimer: This report contains quotations from interviews conducted in the course of the research and contains language that may offend some readers.

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Scientific summary

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Scientific summary

Background

In England and Wales each year around half a million people die, usually after a period of chronic illness such as heart disease, cancer, stroke, chronic respiratory disease, neurological disease or dementia. The two most likely places of death are hospitals (52%) and nursing homes (22%).

End-of-life care in the UK has undergone significant development. In July 2008, the Department of Health published its national End-of-Life Care Strategy (Department of Health. *End of Life Care Strategy: Promoting High Quality Care For All Adults at the End of Life*. London: Department of Health; 2008) to improve the provision of care. The Liverpool Care Pathway for the Dying Patient (or Liverpool Care Pathway; LCP) was promoted as a framework to support care in the last hours or days of life. Optimal implementation of the LCP requires ongoing training and education. Cited as an example of good practice in national publications, the LCP was disseminated as part of the End-of-Life Care Strategy in a variety of settings, including nursing homes and intensive care units (ICUs).

Aim of this study

The aim was to assess the impact of the LCP on care in nursing homes and ICUs. The study was designed to examine the impact on patients, carers, bereaved relatives, nurses, doctors and other members of the multidisciplinary team involved in the care of patients at the end of their lives. The impacts studied included the physical care of the patient; the emotional, social, spiritual and religious needs of the patient; the information/communication needs of carers; and the economic costs of care.

Methods

A detailed pilot study was undertaken to establish the most effective and acceptable ways of approaching patients at the end of their life, their family members and the staff caring for them. A number of issues were identified which were integrated into the planning of the main study. The pilot study and the subsequent main study received ethics committee approval from the North West Wales Research Ethics Committee: the pilot study in April 2010 and the main study in September 2010. Research and development approval was sought and gained in all 12 hospital trusts, and, for the nursing homes, which were under the governance of primary care trusts (PCTs), letters of access were sought for the collection of data.

Study design and sampling

The study sought to generate data that could be used to determine 'impact', and included:

- documentary analysis of Strategic Health Authority (SHA) plans for end-of-life care and collection of end-of-life policy documents
- retrospective analysis of 10 deaths in each location using written case notes
- interviews with staff about local end-of-life care policies and practice
- observation of care of dying patients
- analysis of the case notes pertaining to an observed patient's death
- interview with a member of staff providing care for each of the observed patients
- interview with a bereaved relative who had been present during the observation
- economic analysis focusing on the 25 observed cases.

The study was planned as a matched case design. Great care was taken to ensure that potential comparison sites were as similar as possible, varying in whether or not the LCP was in place to guide end-of-life care. Inclusion and matching criteria were defined for this purpose.

Site inclusion criteria

For nursing homes:

- 24-hour, 'on-site' nursing care
- within travelling distance of the location of the researcher and each other.

For ICUs:

- level 3 care
- under the clinical direction of an intensivist
- > 400 admissions per year (amended early in the study to > 6 level 3 beds)
- > 80% of patients mechanically ventilated
- general ICU (e.g. not heart and lung, burns, neurological specialty)
- within appropriate travelling distance of the location of the researcher and each other.

Matching criteria

For nursing homes:

- provider type
- type of care
- size of home
- Care Quality Commission (CQC) rating
- geographical locality (based on postcode)
- deprivation rating.

For ICUs:

- number of beds
- geographical locality.

The study aimed to recruit 24 sites, 12 ICUs and 12 nursing homes, split equally between sites in the north and south of England. Half were selected on the basis that they used the LCP to support end-of-life care and half were selected because they did not use the LCP to support end-of-life care. Despite considerable investment of time and human resource in recruiting sites, the final sample comprised 11 nursing homes and 12 ICUs, with 23 sites in total recruited to the study.

Shortly after the commencement of this study, the SHAs were disbanded and responsibility for end-of-life care was transferred to PCTs and NHS regional offices. Therefore, the documentary analysis of the SHA plans originally planned to contextualise this study was refocused to include the collection of specific organisational policies and procedures expected to more directly underpin the delivery of care. The data on which this study is based, therefore, are as follows:

1. collection of local end-of-life policy documents in 23 sites
2. retrospective analysis of 230 written case notes: 110 in nursing homes (thematic analysis due to the paucity of information recorded) and 120 in ICUs (discourse analysis of more comprehensive recording, particularly regarding communication)
3. interviews with 138 staff across sites about end-of-life care policies and practice (point 1): 72 in ICUs and 66 in nursing homes

4. 25 observations of care of dying patients in 12 sites: 8 in nursing homes ($n = 4$ sites) and 17 in ICUs ($n = 8$ sites)
5. analysis of the case notes pertaining to the 25 observed patients' deaths
6. 26 interviews with staff providing care during the observation period (point 2)
7. 22 interviews with bereaved relatives who had been present during the observations
8. economic analysis focusing on the 25 observed cases.

Results

It was not possible to meet the stated aims of the study. Although 23 sites were recruited, deaths were observed in only 12. The majority of these were LCP sites. In ICUs, five out of eight sites reported using the LCP, and in the nursing home sample two out of four sites reported using the LCP. As data collection progressed, it became clear that the presumed distinction between a LCP-using and a non-LCP-using site was often blurred. For example, nursing homes which classified themselves as not using the LCP either had very similar end-of-life care pathways in place or started to use the LCP during the data collection period. ICUs which purported to use the LCP did not always do so, particularly where deaths occurred very quickly after the withdrawal of active treatment. Interestingly, although all of the participants in the study suggested that the LCP helped to standardise the approach to care, the data revealed wide variations in the interpretation and implementation of the LCP across the sites, with the greatest variation in the ICU setting.

Although not able to address the original research question, this study provides an unprecedented insight into care at the end of life in two different settings. It also provides some key methodological messages for conducting studies at the very end of life.

The care of dying people in nursing homes

There were no real detectable differences between homes that operated the LCP and those that did not. Eight observations were undertaken in nursing homes and all of these homes used either the LCP or something similar with a different name.

The data from the nursing homes generated some general issues regarding care at the end of life. Training for end-of-life care in nursing homes was variable and often minimal, ranging from watching a DVD (digital versatile disc) to attendance on a 1-day course. Specific issues relating to the provision of care in this setting arose during the case note analysis, interviews and observation.

Nursing home notes did not provide a very detailed account of what had been communicated to relatives in the last days and hours of a patient's life. The patient notes offer a channel of communication for staff as well as an account of the care that has been given. The absence of detail leaves open the possibility of gaps in knowledge, which may contribute to an inconsistent approach among staff to the care of a patient.

All staff interviewed reported the importance of advance care planning in achieving a 'good death'. However, it appeared that the desire to understand an individual's wishes about care at the end of life could result in conversations with patients very soon after, if not on, the day of the patient's admission. The staff reported that some patients and their relatives were upset by these discussions but this did not seem to affect the overall approach, which was to have some idea as early as possible about what should happen if the patient's condition irreversibly declined.

There was a strong emphasis in the nursing homes on being prepared for a patient's death. This did result in the prescribing of anticipatory drugs, just in case they were required, despite the fact that they were rarely used. Issues in achieving a timely visit from the general practitioner also created problems for the nursing homes and often meant that decisions relating to end-of-life care were taken by nurses.

The observations highlighted a number of issues in nursing home care. Although no formal assessments of mental capacity were observed or documented, unresponsive patients were deemed to lack such capacity, and this determined the type and delivery of care, largely the maintenance of the patient's bodily integrity (containing leakages, odour and skin integrity). Family members were not often invited to be involved in providing care, nor were they kept fully informed about the care that had been provided to the patient when they were not present. The absence of formal assessments for swallowing also precipitated attempts at feeding and drinking up to the point of death, occasionally with distressing results for the patient.

Although the staff interviewed thought that the LCP could facilitate a comfortable and peaceful death for the patient, whether or not the LCP had been specifically used in their case was largely irrelevant to relatives. Good care was good care and, in the main, the relatives thought that the care their relatives had received had been good.

The care of dying people in intensive care units

Care of the dying in ICUs looked very different from that in nursing homes. All patients admitted to ICU had been admitted because there was some prospect of recovery. In this context the death of the patient was not expected. Once the clinical team recognised that the patient's condition had begun to deteriorate, the staff began a process of communicating this to the relatives. This was evidenced in the analysis of the notes, the interviews with staff (points 1 and 2), the observations and the interviews with bereaved relatives. One of the major goals of the communication was to arrive at a shared understanding of the patient's condition.

Care of the dying in the ICUs was inextricably linked with the recognition of dying and with the withdrawal of active treatment. Although withdrawal was identified as a clinical decision, and more specifically a consultant decision, there was an emphasis on the clinical team being in agreement and playing a role in the decision-making. The relative's agreement was also seen as desirable, although all staff were clear in emphasising that the relative was not being asked to make a decision about withdrawal.

The observations in ICUs were undertaken in both LCP-using and non-LCP-using sites. In the ICU there appeared to be a subtle difference between LCP and non-LCP care in relation to that provided once withdrawal of treatment had taken place. Nurses in LCP settings reported greater control over care at this time because they had the LCP. As the care of the patient became a nursing responsibility post withdrawal, it may be that in LCP-using sites nurses felt that they had a protocol to follow, while nurses in non-LCP-using sites felt that they had to refer any questions they had to the medical team. In general, it was difficult to assess how the LCP was actually used. It was not clear even from the observations whether the LCP supported practice in that it shaped what was done or whether it was used to account for what had been done, or both. Although all ICU staff identified the LCP as a comprehensive protocol to support end-of-life care, concerns were raised about the length of the documentation and its limited application to deaths that occurred quickly.

Few relatives had heard of or understood the LCP. With very few exceptions relatives reported that the care of the patient had been good, with a dignified death free from suffering and pain achieved. All data sources emphasised the importance of clear communication in ICUs care at the end of life.

Economic evaluation

The economic evaluation was based on the observations of care, and the interviews with bereaved relatives. This provided the research team with access to the way in which participants interpreted and responded to each item in the tool. This tool, in conjunction with the observational and resource data, provided a strategy for calculating comparative costs and benefits experienced by patients supported in LCP-using and non-LCP-using sites in the last hours of life.

The results obtained should be interpreted as indicative rather than definitive, as despite attempts to 'match' service providers the comparison inevitably contained a range of confounding factors. Many 'non-LCP-using' units were found to utilise aspects of the LCP process, and ICUs using the LCP to support care varied in their application of it. Although the ambitious aims of this economic analysis were not achieved, a possible approach to collecting and analysing data for economic analysis at the end of life has been achieved. This now needs to be tested in future studies.

Conclusions

This study was designed to examine the impact of the LCP on care at the end of life in ICUs and nursing homes. As a result of the skewed recruitment of patients in the observation stage and a blurring in the distinction between LCP-using and non-LCP-using sites, it was not possible to meet the stated aims of the study. However, the study provides unprecedented insights into the care provided to patients and their families at the end of life in these settings.

All of the participants in the study suggested that the principles underpinning the LCP supported good care. However, one of the very striking features of the study was the wide variation in how the LCP was interpreted and used across sites, particularly in the ICUs. In most cases, care by clinical staff in both settings was perceived by relatives to be good. The study also demonstrates the challenges of working and researching in a highly sensitised and politicised area of service delivery. More research is needed in to the ways in which an organisational culture can be created within which the principles of good end-of-life care become translated into practice.

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Editorial contact: nihredit@southampton.ac.uk

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