

**Use of the proportion of patients dying on an End of Life Pathway as a quality
marker : Considerations for interpretation**

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Abstract

The Department of Health as part of its End of Life Care Strategy has developed a set
of markers as a quality of care proxy for adults at the end of life. ¹

“The number / proportion of patients dying with the Liverpool Care Pathway (or
equivalent) in place” is suggested as a quality metric for all care providers. ¹

A retrospective audit of uptake of use of the Liverpool Care Pathway (LCP) in an
NHS Hospital in the North of England showed that 39% of all patients who died had
been placed on the LCP. Overall 58% of patients who died were judged to meet the
criteria for LCP use. This represented 81% of patients dying with cancer as a primary
cause compared to 51% of patients dying with non-cancer. This difference was
statistically very significant. In the Trust under study, 67% of dying patients who
fulfilled the LCP criteria were placed on the pathway. The results of this study

suggest that a simple percentage of deaths on the pathway is an unsophisticated statistic which needs to be interpreted with care. In particular it will be influenced by the proportion of people dying with cancer or non cancer. This should be considered particularly when presenting the results to the public and to healthcare stakeholders or when making comparisons between provider organisations.

Key Words: End of life; Liverpool Care Pathway; audit; cancer; non-cancer; quality marker

Introduction

In 2008, the Department of Health published the first comprehensive framework aimed at promoting high quality care for all adults approaching the end of life. ²

This End of Life Care Strategy has subsequently developed a set of markers as a measurement of quality of care for adults at the end of life. ¹ “The number/proportion of patients dying with the Liverpool Care Pathway (or equivalent) in place” is suggested as a quality marker for all care providers. ¹

The Liverpool Care Pathway (LCP) provides an evidence based framework for the delivery of appropriate care for dying patients and their relatives in a variety of settings. In 2004, NICE endorsed the use of the LCP. ³ The DoH then recommended use within the End of Life Strategy in 2008 and in the quality markers and measures for end of life care that were subsequently published in June 2009 ^{1,2} The LCP has been shown to facilitate holistic care and appropriate standards of record keeping in end of life care. Although first developed for use with cancer patients, it is now being modified to be used for other conditions.

The LCP is used when the clinical team expect death to occur within the next 1-2 days. The decision to commence the pathway is based upon specific criteria including an agreement within the clinical team that the patient is dying and that two from the following four criteria apply - the patient is (i) bed bound, (ii) semi-comatose, (iii) only able to take sips of fluids and (iv) is no longer able to take tablets.

The Marie Curie Palliative Care Institute, Liverpool in collaboration with the Royal College of Physicians currently lead an audit of LCP use in hospitals - the National

Care of the Dying Audit - Hospitals (NCDAH) ⁵ . The first audit was undertaken in 2006/7 and the second in 2008/9.

This paper presents the results of an audit of LCP uptake in an NHS Foundation Hospital in the North of England and considers whether the audit measure “The number/proportion of patients dying with the Liverpool Care Pathway (or equivalent) in place” is an effective and representative quality metric.

Method

A retrospective review of case notes of all adult patients dying in the hospital between October to December 2008 (inclusive) was undertaken by a nurse consultant (MM) the lead nurse for cancer and palliative care in the Trust.

Each death was reviewed to see whether the LCP had been used. All deaths were categorised as to whether the primary cause of dying was cancer or non-cancer. For those patients on the LCP the primary diagnosis listed on the pathway was used. For those patients who died but were not on the pathway, the primary cause of death as recorded on the Trust’s documentation of death sheet was used. In cases where patients were not commenced on the LCP, the reviewer (MM) scrutinised the medical and nursing records in the case notes for the 3 days prior to death to consider whether the LCP could have been appropriate. This was based on his expert opinion as to whether there was an implicit diagnosis of dying documented in the notes and if the patient’s condition fulfilled the criteria for the use of the LCP.

The study was approved by the Trust’s Clinical Effectiveness Unit following the Trust governance procedures and this research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

Results

There were 434 deaths of adults for the period October to December 2008 (inclusive). Case notes were obtained and scrutinised for 407 (94%). The remaining 27 sets of notes could not be located during the time of the study.

Table 1 shows the number of patients whose primary cause of dying was cancer or non-cancer and who were in one of three categories (i) placed on the LCP, (ii) not on LCP and could/should have been and (iii) appropriately not on LCP.

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Of the 407 patients who died 93(23%) were attributed to a primary cause of cancer and 314 (77%) to non-cancer .

Of all patients dying 157/407 (39%) did so with the LCP in place. This represents 51/93 (55%) of patients with a primary cause of dying as cancer and 106/314 (34%) of patients dying from a non-cancer cause.

Of all patients dying 236/407 (58%) were eligible to be placed on the LCP. This represents 74/93 (81%) of patients with a primary cause of dying as cancer and 161/314 (51%) of patients dying from a non-cancer cause.

The LCP was used in 157/236 (67%) cases where the patient was considered to fulfil the criteria; this included 51/75 (68%) for cancer and 106/161 (66%) for non cancer. In 171/407 (42%) of deaths the use of the LCP was not assessed as appropriate; this represented 18/93 (19%) deaths of patients with cancer and 153/314 (49%) with non cancer. This difference was statistically very significant (Chi Square $p < 0.001$).

Discussion

Management of patients who are dying is a core provision within general hospital care. In England around 58% of people die in a hospital setting ⁴. We believe that our results compare well with the national picture as 59% of the local population die in the NHS hospital under study, representing 1500 hospital deaths each year. Those who were admitted and subsequently died during the same admission were calculated to take up 21,248 (9.8%) total bed days in 2006/7 and 19,078(9.3%) total bed days in 2007/8. ⁶

Within the hospital under study 39% of patients who died had been placed on the LCP. What does this indicate about the quality of care? This study showed that 58% of all adult patients who die qualify for LCP use. Of the remaining patients, the deaths were not predictable or patients did not fulfil the LCP criteria. Many of these were sudden unexpected deaths or deaths that occurred during active treatment. The study suggested that the LCP could be used in almost 80% of patients whose primary cause of dying is cancer. However, it was found to be applicable to only half of those dying with other diseases - in this study this represented three quarters of all hospital deaths.

Use of the LCP depends on the clinical team diagnosing dying. To be placed on the LCP a diagnosis of dying needs to be made. This is not a precise science and a recent study showed 87% of patients are recognised as dying in the last 72 hours before death.⁷ It may be argued that diagnosis of dying is 'easier' in patients with cancer as it has a more predictable disease trajectory of gradual decline than in patients with end stage respiratory or cardiac disease. Patients with organ failure, particularly those with end stage respiratory disease, are regularly admitted to hospital with acute episodes of illness caused by an exacerbation of their condition which requires active treatment.⁸ This study showed that the clinical prognostication and uptake of LCP usage for those dying and fulfilling the LCP criteria was similar for cancer (68%) and non-cancer (66%). This finding suggests that although death may be less predicable in non-cancer patients 51% (161/314) do fulfil the criteria for LCP use. However it also shows that 49% (153/314) of patients with non-cancer did not qualify for LCP use. This needs further research.

Once a standardised numeric headline quality marker is available it may be used to make comparisons between provider organisations. The same statistic can mask differences in care as judged by appropriate use of the LCP. However, the relative proportions of patients dying with a primary cause of cancer compared to non-cancer may substantially alter the overall proportion of people dying with the LCP in place. As an example, a provider dealing primarily with patients with cancer in the palliative phase (e.g. hospice) would expect to have a higher proportion of patients dying on the LCP compared to a provider caring for acutely ill non-cancer patients undergoing

active treatment. Having 39% of all patients dying with the LCP in place (the metric for the hospital under study) may be a relatively poor result for the former provider and very good for the latter.

Results of this study show that 40% of patients dying in the hospital under study were not eligible to be placed on the LCP. These will include sudden death while undergoing active treatment as well as sudden unexpected deaths. The need for good quality of care for this group of patients and their families and how to measure it merits further study.

Limitations of Study

The authors accept that the categorisation of appropriateness of LCP use depends on the judgement of the reviewer (MM). This is subjective but is based on expertise. In addition it is acknowledged that hospital notes are poor at documenting dying. The reviewer had to make expert judgement based on terminology used in the notes including “for comfort only”, “for palliative care”

Practical Points

- The proportion of patients dying with the Liverpool Care Pathway (or equivalent) in place as a metric of quality needs to be interpreted and presented with care
- The LCP may be appropriate for use in substantially less than 100% of all patients who die. (In this study, the appropriateness was measured at only 60%)
- The LCP may be appropriate for use in 80% of patients dying with cancer
- The LCP may be appropriate for use in only half of patients dying with non-cancer as a primary cause
- Comparison between providers needs to take into account the proportion of people dying with cancer and non-cancer as a primary cause of death.
- The quality of care of those patients who die and who were not eligible to be placed on the LCP merits further study (40% in this study)

Conclusion

The results of this study suggest that the percentage of deaths on the LCP is an unsophisticated headline statistic which needs to be interpreted with care. Interpretation needs to take into account the case mix of the health provider under scrutiny. The results will also be influenced by the relative proportion of people dying with cancer or non cancer. A much more meaningful statistic would be the proportion of patients dying on the LCP who were eligible for its use. This should be considered particularly when presenting the results to the public and to healthcare stakeholders or when making comparisons between provider organisations.

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Table : *The number of patients whose primary cause of dying was cancer or non-cancer and who were (i) placed on LCP, (ii) not on LCP and could/should have been and (iii) appropriately not on LCP*

	Cancer	Non cancer	Total
On LCP	51	106	157
Not on LCP (LCP applicable)	24	55	79
Not on LCP (LCP not applicable)	18	153	171
Total	93	314 *	407

* Chi square $p < 001$