► Continuous quality improvement in care of the dying with the Liverpool Care Pathway for the Dying Patient

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Summary

In order to illustrate the usefulness of a continuous quality improvement approach in care of the dying, this paper focuses on the process and outcomes of the first National Care of the Dying Audit in Hospitals in England. One hundred and eighteen individual hospitals delivering care to patients in the last hours and days of their lives using the Liverpool Care Pathway for the Dying Patient participated in the audit and provided 2672 patient datasets. The results illustrate both that important information can be gained about care delivery using this method and that the opportunity to engage in formal and collaborative reflection, discussion and action planning is useful in promoting continuous quality improvement. This process is likely not only to be of interest to clinicians working in the field but also to managers and planners striving to ensure continuous quality improvement for patients and carers and to inform the process of benchmarking for the future.

Continuous quality improvement

Continuous quality improvement (CQI) within health-care systems is a cyclical and iterative approach to change that involves 'examination of existing processes, change, monitoring the apparent effects of the change and further change'.¹ Because not all change qualifies as improvement, it is imperative that objective data are collected and analysed throughout the process to monitor effectiveness.

Care in the last days of life

The importance of delivering high-quality care for patients in the final hours and days of their lives has been recognized at UK government level in recent years.^{2–4} The hospice sector is commonly regarded as the provider of 'gold standard' care for dying patients but only around 4% of patients actually die in this environment in the UK, while 56% die in acute hospitals.⁵ The challenge is to provide a robust mechanism to translate salient elements of the care provided in the hospice environment to other care settings. The

Liverpool Care Pathway for the Dying Patient (LCP) is a multidisciplinary template of care for the last hours and days of life that can be used in all generic and specialist health-care environments.⁶ The LCP resides within an implementation framework that includes education and training regarding its use, change management techniques to facilitate uptake and sustainability and formal reflection including audit and benchmarking. The LCP has been recommended in UK Government Policy^{2,3} as a means of supporting health-care professionals in the delivery of quality care.

The LCP CQI programme

The LCP Framework is an important programme within the portfolio of the Marie Curie Palliative Care Institute Liverpool (MCPCIL) and the National End of Life Care Strategy,³ and the process of LCP implementation begins with registration of the health-care setting with the MCPCIL. Two specific opportunities to receive formal education about the framework and to network with others using it are built in early in the process. The Foundation Study Day introduces the document and the implementation process and the Advanced Study Day focuses mainly on promoting discussion and debate regarding the experience of implementation. A text book⁶ and other educational materials are also used to underpin learning.

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Formal data collection and analysis also occurs relatively early on to underpin the process of implementation locally. A base review, that is, an audit of documented care of practice prior to implementation, is undertaken in the chosen pilot site at the beginning of the process. The embedding of the document within the pilot site is facilitated through informal but ongoing reflection each time an LCP is used within the environment. Appropriate education and support, often linked into and supported by local specialists in palliative care, is provided as required. A local audit of the first set of pathways (usually 20) is then carried out to allow more formal reflection on the effectiveness of the new 'system' for care of the dying. Both the base review and the post pilot implementation audit are analysed by MCPCIL in support of registered sites. The fact that currently over 1800 organizations are now registered with the LCP Framework from the UK health-care economy, makes gathering such comparative data on a national basis both appropriate and possible.

Spread and sustainability of the framework beyond the pilot area within each environment are important. These are supported by gathering data from a range of 'similar' organizations and compiling a set of data-driven 'benchmarks' against which comparative performance can be assessed. The design of the LCP and the standardized approach to care delivery inherent in its use makes the extraction of data for comparative audit purposes a relatively simple process. While such data is not necessarily comparable with robust research findings, it can be a useful catalyst for debate and improvement. This is particularly relevant in care of the dying, where robust research is morally, practically and ethically challenging. Feeding back such data into each environment in a non-threatening way, reflecting upon the issues raised in regional workshops and developing action plans to improve care locally maintains and promotes the profile of care in the last days locally, regionally, nationally and even internationally (Figure 1).

Method

A National Care of the Dying Audit in Hospitals in England (NCDAH) was undertaken by the MCPCIL in collaboration with the Royal College of Physicians in 2006/2007. The primary aims of the audit were to enable participating hospitals to identify the quality of their care for dying patients as documented on the LCP and to allow them to compare their performance with other participating hospitals and action plan for future delivery.

A retrospective audit design was used to gather data relevant to each of the goals of care on the LCP from up to 30 consecutive deaths in each of the participating hospitals between 1 September 2006 and 30 November 2006. Pertinent patient and hospital organizational data were also gathered to contextualize the data from the

Figure 1 LCP CQIP model. LCP CQIP = Liverpool Care Pathway for the Dying Patient Continuous Quality Improvement Programme

LCP and to aid interpretation of the results. Data were primarily analysed using descriptive statistics and participating hospitals received a report of their own performance against the aggregate performance for all patients.

Between three and six months after these reports were sent out to participating hospitals, a maximum of three representatives from each hospital took part in one of three regional workshops. The workshops gave participating staff the opportunity to revisit the findings, network with others, identify barriers and facilitators to future care and to begin the process of action planning for future improvement. Participants were asked to complete an exit questionnaire about the perceived value of reports, the workshops and participating in the audit. Most questions required participants to rate their agreement with a series of statements on a 5-point scale from strongly agree to strongly disagree.

Results

The following results are presented as examples of how the use of data and reflection contributes to the CQI process:

- First, performance on a selection of goals of care from within the LCP is included to highlight the type of useful information that is available both at a national level and for individual hospitals wishing to improve their performance;
- Second, information from the exit questionnaires regarding participants' perspectives on participation in

the audit and workshops is presented along with a brief overview of the main themes that emerged.

Audit sample

Two hundred and nine hospitals were deemed to have the potential to participate in the audit. Of these, 118 (57%) hospitals submitted data from a total of 2672 patient cases. Fifty-two hospitals (44%) were able to provide the full requested sample size of 30 patient data-sets. Two were specialized cancer centres and have been removed from the sample, leaving data from 50 hospitals (representing 1500 patients).

Hospital demographics

The median number of wards and beds along with the annual deaths within the hospitals in this sample suggests that these were relatively large organizations. Just under 20% of the patients who died in the data collection period received their care in the final days via the LCP. The vast majority of hospitals (97%) had a Hospital Specialist Palliative Care Team and nearly three-quarters had an LCP facilitator, or equivalent, working in the environment. More than 70% of hospitals offered some level of ongoing care of the dying education, particularly for medical and nursing staff. While nearly three-quarters of hospitals had undertaken a formal audit of the LCP in the last 12 months, only 11% had also sought the views of carers regarding care of the dying (Table 1).

Patient demographics

A majority of patients were women with an average of 81 years at death. Fewer than half (45%) had a diagnosis of cancer and they were on the LCP, on average, for just under a day and a half (33 hours).

Table 1 Hospital demographics

Size (median number of wards and beds and IQRs)	
Wards	30 (IQR 20–41)
Beds	635 (IQR 399–854)
Deaths (median number of deaths and IQR)	
Annually	1253 (IQR 913–1609)
Three-month data collection period	261 (IQR 212–378)
On an LCP in data collection period	50 (IQR 39–71)
Personnel (percentage of hospitals with the following personnel in place at the beginning of the audit period)	
Hospital specialist palliative team	98%
LCP facilitator	71%
Ongoing care of the dying education (percentage of hospitals in which this was available for the following members of staff)	
Medics	82%
Nurses	88%
Non-qualified staff	74%
Audit in the previous 12 months (percentage of hospitals in which an audit of care of patients who had died on an LCP and the percentage of hospitals in which a survey of carers' perspectives have been carried out)	
LCP use	70%
Carers' perspectives	11%

IQR = interquartile range; LCP = Liverpool Care Pathway for the Dying Patient

Interpretation and application of the results from goals of care

Feedback is given for a sample of goals on the LCP, chosen, in the main, to illustrate important differences in the level of performance for different goals of care and between hospitals in the sample. A series of box-plots illustrate the relative performance of hospitals in the sample regarding the percentage of goals of care marked 'achieved'. The box plots illustrate the spread of percentage of achieved goals for each hospital with the highest and lowest values for individual hospitals (not defined as outliers) represented by the 'whiskers' above and below the green boxes. The green boxes themselves illustrate the percentage of achieved goals for the middle 50% of hospitals and the median value is represented by the thick black line within each box. An 'outlier' is represented by a 'circle' highlighting those hospitals whose percentage achieved falls more than one and a half 'box lengths' above or below the green box. An 'extreme outlier' is represented by a 'star' highlighting those hospitals whose % achieved falls three box lengths above or below the green box (Figures 2 and 3).

Patient comfort is the main focus once the decision has been made that a patient is unlikely to survive the current episode of care and is now in the last hours and days of life. Having medications prescribed for the most commonly occurring symptoms so that they are available should they be required is an important element in the drive to ensure patient comfort. The results from this audit illustrate that for the majority of patients and within the majority of hospitals, these medications have been prescribed appropriately. Similarly, in the vast majority of four hourly assessments made in the last 24 hours of life, patients were found to be comfortable in terms of these symptoms. In the main, this information provides important positive feedback to teams, but those hospitals that identify themselves as 'outliers' can also pinpoint areas for improvement.

There are some interesting variations in performance that are worthy of note. For example, apart from dyspnoea, overall the median level of prescribing for respiratory tract secretions (RTS) is lower than for the other symptoms and the median level of comfort in terms of RTS is also lowest. At the individual hospital level, hospitals that appear as outliers for PRN (as required) prescribing also tend to appear as outliers on levels of comfort for those symptoms in the last 24 hours of life. Such information may highlight the need for further investigation of practice to facilitate improvement. The prescribing of medication for dyspnoea is less consistent across the board, which may be due to the fact that this is a relatively new goal on the LCP and that the medication prescribed for dyspnoea is likely to be the same as that prescribed for pain. The latter may also be implicated in the finding that the comfort of patients in terms of dyspnoea does not appear to be unduly compromised.

The relatively greater variation apparent in the level of discontinuation of intravenous fluids/medications may reflect individual clinician decision-making to continue with such interventions in the best interest of the patient.

Figure 2 Domain 1: physical comfort of the patient – anticipatory prescribing and discontinuation of inappropriate medical interventions ($n = 50$ hospitals). PRN = as required; RTS = respiratory tract secretions; IV = intravenous; CPR = cardio-pulmonary resuscitation. Note: Please see online article for colour version of figures

Certainly, the percentage coded 'variance' in this sample is relatively high for this goal and an analysis of the variance sheets in individual hospitals should give more information about these decisions. For this reason, the second round of the audit will seek information from the variance sheets to aid interpretation at the national level (Figure 4).

The results for psychological and spiritual/religious aspects of care and communication clearly illustrate much greater variation across the board and much lower levels of achievement of these goals of care, particularly for the patient and communication with the general practitioner

(GP). However, even here, the results do highlight those hospitals where performance is outside the norm. Hospital 7, for example, is achieving certain patient-focused goals in 100% of cases, while others are falling below the 'norm' for certain carer-focused goals (NB those patients coded 'comatose' at the time of assessment have been excluded from the sample compromising the sample size within some hospitals). Reflecting on and using these results again has the potential to open up the debate within and between hospitals to identify education and training needs.

Figure 3 Domain 1: physical comfort of the patient – ongoing assessment of symptoms ($n = 48$ hospitals). RTS = respiratory tract secretions; N&V = nausea and vomiting. Note: Please see online article for colour version of figures

Figure 4 Domains 2 and 3: psychological and spiritual/religious aspects of care and communication ($n = 50$ hospitals). GP = general practitioner. Note: Please see online article for colour version of figures

Workshop sample

An important part of using data to promote continuous quality improvement is taking the opportunity to bring individual practitioners from each hospital together to discuss the implications of the results, to share good practice, to learn from each other's experiences and action plan for improvement. A total of 120 health-care professionals attended the three workshops and 115 completed exit questionnaires. The majority of respondents were members of the nursing profession (83%).

Interpretation and application of workshop results

Workshop questionnaire results

More than 90% of participants agreed (i.e. either agreed or strongly agreed) that the report contained the right amount of information and that the information was useful. Eighty-five percent agreed that the information was easy to understand. There was an overwhelmingly positive view of the usefulness of the workshops in terms of sharing elements of good practice, gaining a better understanding of the data and beginning the process of action planning for improvement (>90% agreement). Eighty-eight percent of participants thought that participation in the National Audit would make a difference to care of the dying in their own organization.

Workshop main issues

During each workshop, participants were asked to identify barriers to the delivery of good end of life care that they thought were impacting in their own environments. This information was themed by the workshop facilitators on

display boards and was then further clarified and discussed in the open forum. Participants were then asked to identify potential solutions to the barriers previously identified along with any examples of good practice. In a similar manner, these items were themed by facilitators in discussion with the group. The main issues identified included raising the profile of end of life care both nationally and locally, particularly embedding it within already existing structures. The importance of LCP facilitators, novel and appropriate education and training, as well as ongoing audit and making the best use of the LCP in terms of diagnosing dying well and ensuring compliance with the document were also raised. A summary of the major topics of discussion at the workshops and examples of good practice can be viewed in more detail at www.mcpcil.org.uk.

Participation in the workshops, which encouraged further reflection on the results, was generally positively viewed. Further reflection and discussion allowed individuals to 'tease' out the issues underlying performance and to share areas of current good practice in response to these issues. Action planning for the future, which also began as part of the workshop process, will, hopefully ensure a clear focus for change within individual hospitals.

Discussion

The main purpose of this paper is to illustrate how the process of CQI, particularly the appropriate use of objective data, can encourage critical reflection on current clinical practice around care of the dying, and can enable education and training to be focused appropriately to encourage improvement in the quality of care. The audit data itself

are useful for reflecting back findings set against a standard of care, in this case the LCP, and offers important insights on several levels. First, they illustrate at a national level which goals of care are routinely achieved for patients in the dying phase, as well as identifying those goals where improvement is required. Second, at individual hospital level, it is possible to compare one's own performance with that of others to identify where performance falls below the standard of others, and therefore, where future education and training should be focused. This opportunity to reflect on one's own performance in comparison with that of others nationally is invaluable in promoting continuous quality improvement in care of the dying.

A second round of the NCDAH is currently underway. Analysis of the results of the first round have led to the inclusion of additional questions that will drill down further into interesting elements of care such as reasons for non-compliance with the discontinuation of intravenous fluids/medications and the reported level of medication for the alleviation of agitation and restlessness in the last 24 hours.

The LCP was originally developed in the late 1990s as a local initiative to enable the transfer of best-practice in care in the final hours and days of life from the hospice environment to the acute setting. Over the years, this simple framework has captured the imagination of thousands of health-care workers working in a variety of settings, firstly in the UK but more recently, across the world. The LCP is consistently under review and development based on feedback from users, and after an extensive national and international consultation process, Version 12 of the document will be launched in the autumn of 2009.

Currently, over 1800 sites (acute hospitals, community hospitals, hospices, GP practices, district nursing services and care homes) are registered to use the LCP in the UK. In addition, over 200 sites are registered from 18 countries outside of the UK and the LCP document, along with associated supporting material, has been successfully translated

(using EORTC Guidelines) into several different languages. Importantly, throughout this process of widespread dissemination and translation, care has been taken to ensure that the meaning and intention behind each of the goals of care on the LCP has been preserved. This will theoretically allow data aggregation similar to that within the NCDAH to be undertaken more widely in the future.

Certain international partners have been associated with the LCP programme for many years and have developed regional or national programmes for the 'roll out' of the LCP within their health-care communities. For example, the Netherlands have been using the LCP for around 10 years and, following a PhD study to evaluate the effectiveness of the LCP in care in the last days and hours of life,⁷ a national 'roll out' of the document has recently begun. In Italy following a successful pilot, a regional cluster randomized-controlled trial to evaluate the impact of the LCP will shortly begin to run alongside the regional implementation of the LCP in the hospital sector.

Clearly, the LCP is an example of how a locally developed integrated care pathway can become relevant in the global health-care community to drive the delivery of high-quality care for patients in their last hours and days of life.

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