

COMMENTARY

The demise of the Liverpool Care Pathway: should we ban the highway code because of bad drivers?

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Abstract

The Neuberger report failed to show that the Liverpool Care Pathway was the cause of poor end-of-life care and made it the scapegoat for poor communication and faulty decision-making. The report's discrediting of a quality assurance mechanism that had the potential for improvement is a disservice to dying patients. Several of the report's recommendations are puzzling, but two consequences of the report, an excellent review of care pathways and a recommendation to establish a national end-of-life coalition, have the potential to improve care of the dying individual.

Keywords: Liverpool care pathway, end-of-life care, Neuberger report, care pathways, quality assurance, older people

On the 15 July 2013 the Liverpool Care Pathway (LCP) was given a terminal diagnosis. So how did this happen to a document that for the last decade has received repeated clean bills of health from NICE [1], the Department of Health [2], the GMC [3], the CQC [4], several royal colleges, specialist organisations, a succession of national policy frameworks [5, 6] and which the LCP review panel noted 'can provide a model of good practice for the last days or hours of life for many patients?' [7].

The symptoms started 2 years previously but the seeds had been sown long before then. The LCP is an integrated care pathway. These are patient-centred multidisciplinary care plans that identify the care needed for patients with specific problems and provide a means of auditing that care [8]. Such pathways exist throughout clinical care, but the LCP had an Achilles heel in its title. No-one has a problem with a pathway to recovery, but a pathway with death as an endpoint was always open to misinterpretation. The first comments started several years ago, reaching a peak at the end of last year with media stories of the LCP causing malnutrition, dehydration and premature deaths in adults and newborns alike. This prompted Norman Lamb to set up a LCP review panel under Baroness Neuberger. The panel's eventual remit went well beyond the LCP and covered the whole trajectory of care in the last months and years of life. Published under

the title *More Care Less Pathway*, [7] one of its actions was to commission a review of current evidence on end-of-life care pathways which contains this observation [9]

The lack of evidence makes it particularly difficult to identify whether negative consequences suggested to be associated with pathways for managing the dying phase in end of life care are directly associated with (a) actual pathway-based care, (b) poor implementation of pathway-based care, and/or (c) emotional consequences of illness, death and bereavement.

This uncertainty did not prevent the LCP review panel from recommending that the LCP name should be abandoned, the term 'pathway' avoided, terms to define all pathways be urgently reviewed and that the LCP should be replaced within 12 months by an 'end of life care plan'. This is despite the panel noting the clear benefits of the LCP when used correctly and, most importantly, rejecting the accusation that the LCP was a means of deliberately hastening someone's death. The panel criticised the lack of evidence around the LCP, despite the commissioned review making clear that this problem is shared with all care pathways and that conducting robust trials in dying patients is fraught with ethical and methodological difficulties. Much of the LCP report's 61 pages and 44 recommendations are not new and exist in many papers, reports and

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publications in recent years: the lack of evidence on estimating prognosis; the effect of poor staff numbers and skills; the poor understanding of the Mental Capacity Act; the need to ensure adequate hydration and nutrition; the impact of poor communication and compassion; better training; the lack of research around end-of-life care; poor decision-making; inadequate environments and the value of shared decision-making and shared care records. These are always worth repeating since institutional change is often burdened by a hefty inertia, a fact underscored by Mencap's *Death by Indifference* report [10] being followed by the Winterbourne scandal [11]. However, the report fails to provide evidence that the LCP was the smoking gun and describes a whole host of other reasons for the poor care presented to the review panel.

Some of the review panel's recommendations are puzzling. Their suggestion to replace the LCP with an 'end of life care plan' creates a plan with death as an endpoint, the same criticism they levelled at the LCP. Having recommended the LCP be replaced within 6–12 months the panel also expect the CQC to carry out a thematic review within 12 months of how dying patients are treated, which is rather like setting a handwriting test but confiscating the only pen beforehand. The recommendation to have independent advocates for all patients lacking capacity is challenging, especially the suggestion to supply many from voluntary organisations, but it is difficult to understand why the panel did not simply require compliance with existing capacity legislation. The report criticises 'tick-box exercises', apparently unaware that many complex procedures rely on checklists for safety and that the problem is the lack of thought or care, not the checklist. In their recommendation to phase out the LCP over a year, the most puzzling omission was not to consider the distress of partners and relatives at the mention of a document that had been discredited by a national review.

Over 40 years ago John Hinton wrote 'We emerge deserving of little credit; we who are capable of ignoring the conditions which make muted people suffer. The dissatisfied dead cannot noise abroad the negligence they have experienced' [12]. Hospices and the speciality of palliative care grew from such concerns, with a determination to improve both the care and the science and to do so in all settings. The LCP was part of that determination and was an important means of quality assurance and audit. Poor care and practice continue for reasons that vary from ignorance, poor resources, stress and arrogance to the fortunately rare mal-evidence. The uncomfortable truth is that John Hinton's 'dissatisfied dead' still exist but for a wide range of reasons. Could the LCP have been improved? Of course- it needed a different title, it could have been shorter, LCP audits could have focused more on care delivery than documentation, training should have been mandatory, an accreditation process would have helped and the wording and criteria could have been modified to emphasise its quality assurance aspect while making clear that it was not a route march to death. Could it have been better explained? Many tried, but these explanations were overwhelmed by distressing cases of poor decision-making and inadequate communication.

The Neuberger report does not demonstrate that the LCP itself was the cause of poor care and the impression is that the LCP was made the scapegoat. There are many aspects to this tragedy, but two stand out. Firstly, discrediting a widely used national quality mechanism will ensure that those who remain ignorant or negligent will continue their poor practice without fear of being discovered for the years it may take to produce an alternative. Secondly, the death of the LCP was preventable, an irony that was lost in the rush to pronounce its demise and promote the message of a listening government. It is as illogical to discredit guidance because of errant clinicians as it is to ban the Highway Code because of bad drivers. This was an opportunity to improve what existed, but announcing the loss of a quality assurance mechanism without any plan or thought to its replacement is the real tragedy that is a disservice to dying patients. To deliver a terminal diagnosis without adequate preparation or thought was a strong criticism made by the panel when hearing about poor care, making the panel's actions more pathway than care. However, two lights shine through the mist: the excellent review of pathways by Nottingham University [9] and the LCP review panel's proposal to set up a national alliance looking at end-of-life care. While much of the content in Neuberger's report has been said many times before, these two components have the potential to benefit patients and reduce the number of dissatisfied dead.

Key points

- Neuberger report made the LCP a scapegoat.
 - Several report recommendations are puzzling.
 - Report is accompanied by an excellent review on care pathways.
 - No evidence that the LCP was the cause of poor care.
 - Recommendation for a national end-of-life care coalition is a worthy aim.
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Conflicts of interest

None declared.

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