Editorials

The Liverpool Care Pathway for the dying:

what went wrong?

The recent Independent Review led by Baroness Neuberger[1] recommended discontinuation of the Liverpool Care Pathway for the Dying (LCP). Developed in the 1990s to address barriers to the delivery of excellent care in the final days of life, the LCP was designed to support the high standard of palliative care prevalent in hospices to other clinical settings. It provided guidelines for best practice, focusing on symptom control, appropriate discontinuation of active treatments, psychological, social, and spiritual care of patients and their families, and frequent patient reassessment.

However, in recent months the LCP has come under intense media scrutiny, with the *Daily Mail* describing it as 'a pathway to euthanasia',[2] compromising patient autonomy, used to 'free up hospital beds' and even for NHS trusts' financial gain. Despite widespread support across the majority of the healthcare professions,[3] the Review report is unequivocal: use of the LCP must cease. To examine the underlying issues that have fuelled this controversy, it is pertinent to consider the extent to which the Review's recommendations represent a proper response to legitimate concerns or whether a good clinical tool is being sacrificed to a media furore.

THE KEY ISSUES

The debate surrounding the LCP has revealed a deep reluctance in UK society to address issues of mortality, by patients, relatives and healthcare professionals alike. Hospitals are seen as places to heal and prolong life; acceptance of dying and death is interpreted as giving up, ceasing to try, even as approaching euthanasia. Doctors may have a sense of failure and fear complaints or litigation for not doing enough. Yet from ancient times it has been an integral part of the doctor's role to ease a patient's pathway to death when the time has come, neither hastening death nor prolonging suffering. General Medical Council guidance is clear:

'... it may be of no overall benefit to provide potentially life-prolonging but burdensome treatment in the last days of a patient's life when the focus of care is changing from active treatment to managing the patient's symptoms and keeping them comfortable.'[4]

The LCP sought to operationalise this guidance into practical steps for clinicians.

Sadly, it is undeniable that the Review and the media have highlighted examples of extremely poor practice. Many cases revealed ineffective or absent communication between healthcare professionals and patients or relatives, resulting in appalling care when this happened. However, the LCP repeatedly emphasised the importance of clear and open communication with the patient and family and within the multidisciplinary team. It provided an outline structure to assist the more anxious, inexperienced, or reluctant professional with the difficult areas of communication known to form the basis of the majority of complaints in relation to end-of-life care.[5]

Particular concern was raised in the Review about reports of patients being denied oral fluids, contrary to the legal requirement to provide basic care:

'The offer of food and drink by mouth ... must always be offered to patients who are able to swallow without serious risk of choking or aspiration.'[4].

In fact, the LCP guidance was explicit that:

'... the patient should be supported to take food and fluid by mouth for as long as tolerated.'[6]

The Review also identified reports of withdrawal of nutrition and hydration by drip or tube, without explanation or consultation. Decisions concerning these medical interventions are *'not clear cut in end-of-life care'*.[4] The LCP was clear that *'a blanket policy of no clinically assisted (artificial) hydration is ethically indefensible'*, and that while *'for many patients clinically assisted nutrition and hydration will not be required, the plan of care should be explained to the patient where appropriate and to the relative or carer.'*[6]

A further relevant issue is the uncertainty inherent in identification of the dying phase, especially in non-malignant disease. Most of the cases of poor care reported to the Review body related to the older patients with non-cancer diagnoses. Three-quarters of deaths in the UK are from non-cancer causes, yet these patients make up a minority of patients on GP palliative care registers[7] often only being recognised as needing end-of-life care when very close to death.[8] Criteria for earlier identification of non-cancer patients approaching the end of life have recently been developed,[9] although the communication challenges are compounded by a reluctance to discuss end-of-life care.[10,11] As Sharp *et al* report in this issue of the Journal,[12] it is challenging but crucial to acknowledge the uncertainties of end-of-life care with patients and families, especially in non-malignant disease. Recognising this, the LCP emphasised that *'uncertainty is an integral part of dying'* particularly in patients with less predictable disease trajectories[13] and offered guidance for the difficult task of sharing uncertainty with patients.

THE WAYS FORWARD

The application of any guideline or integrated care pathway without good clinical judgement will result in poor clinical care. Guidelines are written to guide, not to dictate. We are concerned that the vacuum left by the abolition of the LCP makes a return to the 'bad old days' of poor or non-existent communication about dying a real possibility: we would argue that the response to poor use should be right use, not non-use. We welcome the Neuberger Review's call for increased funding and training in palliative care and suggest that skills in end-of-life care should become a required competency for all health

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care professionals. This is identified as a necessary outcome for medical student education in the UK[14] although, as demonstrated by the annual meetings of the Association for Palliative Medicine Undergraduate Education Special Interest Forum, the allocated curriculum time, content and mode of delivery for palliative and end-of-life care still varies greatly between medical schools.

While we suggest that the issues underlying the LCP controversy are best addressed by correct use of the Pathway, it could be contended that the recommendation to phase it out is one of simple pragmatism: a year of relentless media onslaught has led to the public's perception of the LCP 'brand' being denigrated beyond redemption. That being said, the resultant situation leaves us with some serious concerns.

The LCP was designed to apply best hospice practice in settings less well suited to end-of-life care, especially acute hospital wards, intensive care, and accident and emergency units[14] where good end-of-life care may be difficult alongside the need for rapid diagnosis and active clinical management. The LCP provided a framework for non–palliative care specialist clinicians to deliver good end-of-life care in a wide range of clinical settings. The Review recommended that the formal care pathway be replaced with a series of condition specific information booklets.[1] However, dying patients frequently have multiple comorbidities and present with symptoms common to a number of conditions. Such booklets could fragment rather than enhance care and, in the absence of unifying documentation, busy health professionals may simply neglect to use these new resources, reverting to a situation of ad hoc, poorly guided care.

WIDER IMPLICATIONS

Equally concerning are the international repercussions of the Review. The UK was the origin of the global palliative care movement in the 1960s and remains at the forefront of developments. Internationally, palliative care provision still encounters fundamental obstacles and one-third of countries have no hospice or palliative care activities whatsoever.[15] In countries where absolute poverty is prevalent and governments are unable to meet many of the basic health needs of their populations, palliative care is viewed as an unaffordable luxury, although it would in fact enable families to avoid unnecessary spending on futile interventions for dying loved ones. Globally, the LCP has proved a key tool in the development of palliative care in countries as diverse as Argentina, Slovenia, India, Norway, and the Netherlands.[13] It remains to be seen what the repercussions of the Review will be on use of the LCP in settings where the criticisms that have shaped the UK debate may not apply.

The LCP Review comes at a time of intense scrutiny of broader patient safety and care quality in the UK NHS.[16] The current national debate and the Review have revealed incidents of appalling care that raise questions concerning the wider state of the NHS, 'issues strongly echoing those of the Mid Staffordshire Public Enquiry'.[1] Services that provide poor quality general care will undoubtedly provide very poor end-of-life care. Perhaps the LCP is now irredeemable, but as we learn lessons and look to the future, the adverse publicity surrounding it should not be used as a means for politicians and healthcare professionals to avoid tough questions about the culture of care in the NHS.

ADDRESS FOR CORRESPONDENCE

Stephen Barclay
Primary Care Unit, Department of Public Health and Primary Care, University of Cambridge, Institute of Public Health, Robinson Way, Cambridge CB2 0SR, UK.

E-mail: sigb2@medschl.cam.ac.uk

Daniel Knights,
Clinical Medical Student, University of Cambridge School of Clinical Medicine, Cambridge.

Diana Wood,
Clinical Dean, University of Cambridge School of Clinical Medicine, Cambridge.

Stephen Barclay,
University Lecturer, Primary Care Unit, Department of Public Health and Primary Care, University of Cambridge, Institute of Public Health, Cambridge.

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