

Response to the Neuberger review by the International LCP Reference Group

Introduction

An international meeting was held in Liverpool, UK, 26-28 November 2013, attended by leading thinkers, practitioners and researchers in care for the dying from 12 countries.

The group has been working together for a number of years with a shared focus on the Liverpool Care Pathway for the Dying Patient (LCP) under the name the International LCP Reference Group.

The LCP was developed in Liverpool by the Marie Curie Palliative Care Institute Liverpool, a partnership between the Royal Liverpool and Broadgreen University Hospitals NHS Trust, the University of Liverpool and Marie Curie Cancer Care, ⁽¹⁾. It has been used extensively in English Hospitals ⁽²⁾ and has also been implemented by colleagues from the 12 countries represented on the International LCP Reference Group and in thousands of healthcare settings – including hospitals, hospices, care homes and in the community – in 23 countries in total.

From 2009, the LCP became the focus of media attention surrounding end of life care in England, culminating in an independent national review of the implementation of the LCP being established in late 2012, and reporting in July 2013 ⁽³⁾.

In this context the international partners aimed to review the current situation in England and establish the best way forward for international collaboration aiming to improve the care for dying patients and their families.

The English Media, Neuberger Review and the LCP in England

In December 2009 the Daily Telegraph published, as a front-page lead, a letter from a retired geriatrician to the effect that the LCP was being used by hospitals to hasten death ⁽⁴⁾. This led to a significant amount of media attention surrounding the LCP.

Media coverage subsequently followed surrounding round two of the National Care for the Dying Audit Hospitals (NCDAH) ⁽⁵⁾ that misrepresented key elements of its findings relating to the LCP and the care being provided for dying patients. The LCP became the focus of sustained negative media coverage in some sections of the media ^(6, 7, 8), which continued despite the challenging of the misrepresentation and inaccuracy ⁽⁹⁾, more balanced coverage in other media ⁽¹⁰⁾ and the extensive support of clinicians and end of life care charities and other organisations ^(11,12). This culminated in late 2012 in the establishment of the Neuberger Review ⁽³⁾.

The Neuberger Review examined complaints about care from bereaved relatives, conducted a literature review ⁽¹³⁾ and conducted public meetings involving over 300 families and professionals.

Publishing in July 2013, it made over 40 useful recommendations, including covering key issues relevant to the ability of the NHS to provide best quality care for dying patients – importantly the need to address:

- Education and Training
- Research and Development funding
- Access to specialist palliative care services, and
- The need to ensure care and compassion from all involved in caring for dying patients
- A National Debate about death and dying.

It also identified some key challenges in relation to the LCP and its profile and misrepresentation in the media. Crucially, the review found that the LCP is based on the sound ethical principles that provide the basis of good quality care for patients and families when implemented properly ⁽³⁾.

Despite this, the review found that terminology, in particular the word ‘pathway’, were problematic and it was recommended the terms be discontinued. The Review also recommended that the LCP be replaced in the clinical environment in England within 6 to 12 months and be replaced by, as yet undefined, individualised end of life care plans.

Since the Review publication, NHS England has issued interim guidance ⁽¹⁴⁾ advising that Trusts successfully using the LCP should continue its use rather than abruptly stop. A strategic *Leadership Alliance for the Care of Dying People* has been formed supported by a clinical advisory group, to develop an approach to assist clinicians when the LCP is withdrawn ⁽¹⁵⁾. Interim guiding principles have now been issued, with a consultation period to the 31st January 2014. The Chair of the Leadership Alliance has indicated that it is not intended to release any national tool to replace the LCP, rather guidelines, with supporting education and training ⁽¹⁶⁾.

Whilst the publication of the Neuberger Review has resulted in a reduction in media coverage of the LCP, and care for the dying more generally, a debate does continue in the English media and will likely continue for the foreseeable future. Recent coverage has included a number of perspectives, including the risk of a lack of clarity for organisations and clinical teams. It has been suggested that the lack of clarity in the current situation, with some areas withdrawing the LCP with immediate effect, has led to reduced quality of care for dying patients. ^(17, 18)

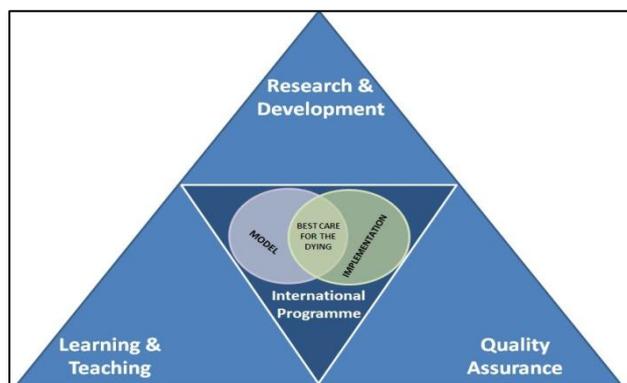
There have also been accusations that the LCP is simply being ‘rebranded’ ⁽¹⁹⁾, raising challenges about the understanding of key issues within established international evidence on the care of dying patients, such as anticipatory prescribing, hydration and nutrition ⁽²⁰⁾. However at the same time it is being highlighted that whatever might replace the LCP is likely to look similar to it ⁽²¹⁾, reflecting that the LCP does indeed reflect the key elements required to provide good care for dying patients ⁽²⁰⁾. Indeed the Lancet Oncology has now warned of the danger at this time of a triumph of politics over evidence in England ⁽²²⁾.

The International Collaborative for Best Care for the Dying Person

As identified in the Neuberger Review, the LCP itself is ethically sound and provides good care when implemented well ⁽³⁾. The International Group reaffirmed its commitment to working collaboratively to achieve best care for dying people in the last hours and days of life.

In doing so the group resolved that the Integrated Care Pathway methodology ⁽²³⁾ must remain central to international collaborative work, supported by International Model Integrated Care Pathway Documentation and an International Model of Implementation.

Fig. 1



To take forward this work, it was agreed to establish ‘*The International Collaborative for Best Care for the Dying Person*’.

The vision of the International Collaborative for Best Care for the Dying Person is for a world where all people experience a good death as an integral part of their individual life, supported by the very best personalised care.

The Marie Curie Palliative Care Institute Liverpool (MCPCIL), University of Liverpool, UK will be the coordinating centre for the International Collaborative.

A Collaborative Response to the Neuberger Review

We are confident that the issues identified in the Neuberger Review reflect challenges in societies and their healthcare systems regarding attitudes towards death and dying and care for dying patients, rather than inherent problems with the LCP itself or Integrated Care Pathway methodology.

The LCP has proved to be transferrable across national, cultural and religious boundaries through the work of colleagues represented on the International Collaborative ⁽²⁰⁾.

Recent English newspaper reports may choose their words carefully regarding “many instances of suspected hastening of death” ⁽²⁴⁾, however the only randomized control trial evidence available with regards to the LCP in practice found no differences in survival times between patients cared for in wards where care is supported by the LCP and those in control wards where the LCP was not used ⁽²⁵⁾, contradicting the un-evidenced claims that the LCP is used to hasten death. Although underpowered, the study also found significant benefits to patients in terms of respect, dignity, kindness and control of breathlessness.

Whilst noting the issues with the term ‘pathway’ in English, this term is not generally problematic in other partner countries. However given the challenges in England, more transparent terminology has been established for the International Collaborative, focusing on *Best Care for the Dying Person* – our overall shared aim – in the naming of the International Collaborative, the Model Documentation and the Model of Implementation.

What is clear, as recognised in the Neuberger Review, is that a sensible societal debate is required regarding death and dying, so that individuals and their loved ones can discuss and prepare for their own death and we as caring professionals can achieve with them an holistic approach to their end of life care as a whole.

The Way Forward

The International Collaborative will now take forward a programme of work to achieve our vision. We are establishing a constitution to support this, developing our core principles based on those established during our previous OPCARE9 collaborative work ⁽²⁶⁾ and bringing forward a programme of collaborative work packages encompassing research and development, quality assurance and learning and teaching work streams.

We remain committed to Integrated Care Pathway methodology supported by robust implementation grounded in organisational and system-wide quality governance.

Quality and safety are key, and we reiterate our view that accreditation is needed in some countries to strengthen the implementation process ⁽²⁷⁾, and the education and training of professionals caring for patients in their last days and hours, so as to more formally embed this care within the core business of and quality governance structure of organisations ⁽²⁷⁾.

For the sake of the patients and families we care for, it is our duty to not allow politics, driven by the media, to triumph over evidence ⁽²²⁾ in England or in any other country. Rather we as a group will continue to rigorously pursue work in support of our vision for a world where all people experience a good death as an integral part of their individual life, supported by the very best personalised care.

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