

The Liverpool Care Pathway – a personal perspective

Dr Hannah Lord (Consultant Clinical Oncologist, Ninewells Hospital and Medical School)

Correspondence to: Dr Hannah Lord : hannah.lord@dundee.ac.uk

ABSTRACT

Dr Hannah Lord provides a personal perspective on the recently debated Liverpool Care Pathway.

Key Words: Liverpool care pathway; oncology; palliative care

Introduction

The Liverpool Care Pathway (LCP) was developed in a Marie Curie Hospice in Liverpool in 1998¹. Its aim was to allow high quality care to be delivered to patients during the final days of their life, irrespective of their location within the NHS.

Its need stemmed from the fact that most patients in the UK (approx. 60%)² die in an acute hospital setting, in busy wards, far from a hospice. In these areas, palliative care experts may rarely be met, and terminal care can vary greatly in quality. By developing this pathway, the intention is to provide care that avoids unnecessary distress, and unnecessary medication and medical intervention, where appropriate, in all hospital wards.

As a care pathway, its use has since spread across the UK. It was accepted by the National Institute for Clinical Excellence (NICE) in 2004³, as a document that supported good practice. It was also approved by the Scottish Government in 2008, in their publication “Living and Dying Well”⁴. It is continuously reviewed, and the latest publication was Version 12, in 2011.

The LCP clearly has laudable aims. To deliver first class palliative care to the dying patient across the NHS.

Controversy

However, it is this very definition of a ‘dying patient’ that has led to accusations against the LCP.

The decision to commence a patient on the pathway should be taken by a senior doctor, in consultation with nurses and family members, when it is thought that the patient has less than 72 hours to live. If in agreement, it is permissible to stop medication that is considered unnecessary, such as antibiotics and other routine treatments; to commence sedation through a subcutaneous drip using morphine

and anxiolytics; and to remove intravenous drips and methods of nutrition and hydration other than mouth care.

The patient will continue to be assessed, and if improvement is found, the pathway should be discontinued and active treatment recommenced. Also the pathway should be reviewed if carers voice any concerns, or the patient remains alive after 3 full days.

Difficulty potentially arises at the first hurdle. Who is able to determine if a patient is within 72 hours of death?

This can be a complex area. In some cases, it can be clear, such as when a patient has widespread and rapidly advancing malignancy, accompanied by overwhelming sepsis or organ failure. At other times, it is much less clear-cut. A patient who has metastatic malignancy and has responded to palliative treatments, now has a severe lower respiratory tract infection causing a potentially life threatening illness in itself. They are given antibiotics, but continue to deteriorate.

What do you do? Continue with intravenous antibiotics?

The patient pulls the venflon out, in confusion. Do you re-site it?

The patient stops eating and drinking. Do you start subcutaneous or intra-venous fluids? Or do you start the LCP?

Communication

The second difficulty (although it should not be seen as that) arises in the need for good communication, in these potentially busy wards. Some relatives and carers have complained that they are not always fully consulted, or clearly involved, in this important decision. Is their relative dying? If so, they need to be informed in an appropriate way. The discussion then needs to be as to how best to manage this extremely distressing time.

Good communication is the key to all good practice, and never more so than in the implementation of the LCP. As with any tool, it is only as good as its user. Discussion with relatives and friends of the patient are imperative, to gauge what the patient him or herself would have wanted and what the family now wishes. Then and only then can appropriate decisions be made.

Meaning

It is important that the significance of the pathway is fully explained to family members. The expectation is that the patient will die, and this pathway is to make that death as peaceful and dignified as possible.

This has led some to call the pathway an “assisted death pathway”⁵, or indeed to question if this is a form of legalised euthanasia. How can a heavily sedated patient, denied fluid, be expected to improve? The pathway is a self-fulfilling prophecy. I expect you to die; so will assist to make that process calmer, even if I hasten death.

This is known as the double effect. This is a philosophical doctrine where an action is taken in the knowledge that it may lead to normally unacceptable consequences, but because it is taken with the intent of a good effect i.e. the relief of suffering, it is in fact permissible. Most people consider this ethically sound.

What do I think?

What have been my experiences?

Well, first of all, I should say that I have never actually used the LCP per se, in its true form. Its ethos is widely implemented however, and I have certainly practiced the same principles.

It was approved by NHS Tayside where I work, two years ago, but it is interesting that it is only used within the hospices and the Renal Ward. It is not used on the Oncology ward. Nor was it used in the Oncology ward in NHS Lothian, where I trained in Oncology.

I would also say that my experiences are “varied”. Each case is individual. In retrospect, I now believe if this is remembered, we are hopefully most of the way there.

I clearly recall early in my Oncology training, seeing a patient on a distant ward in the hospital, far from an Oncology or a palliative care bed. He had advanced lung cancer obstructing his main airway, which had not responded to radiotherapy and he was too unwell for a bronchoscopy or for a stent to be inserted. He had stridor, he was on high flow oxygen and his breathing was becoming more distressed. He knew the end was approaching.

I did not know what to do. How could I help this man, in both physical and emotional distress? I called my Consultant and asked her for advice. She said there was nothing we could do. She said I should start a subcutaneous pump with morphine and midazolam. I knew this would sedate him and he would likely die within 24 hours. I felt I was quite literally “putting him to sleep.” I did as she said, but felt terrible as I explained to him that I was going to give him some medicine that would help him to feel a bit more relaxed. I then left the ward, us both knowing we would never see each other again. He had no family with him. He knew he was dying. I felt it was a bad death.

The reason I felt that way was mostly because there was no family there to discuss the decision with, and no chance for this man to say goodbyes. No next of kin were identified. But I felt uncomfortable. I am sure he died peacefully, and without the medication, he would have become more breathless and distressed and would have died a more unpleasant death. But the premeditated nature of putting up the pump left me feeling awkward.

On other occasions, the decision has been without doubt the correct one. In those patients who have had time to understand their illness, who have had time to absorb that the outlook is limited, and where the family feels all that could be done has been done, a calm and dignified death without undue medical intervention is

exactly what they would wish. The Liverpool Care Pathway legitimises that and gives a framework for nursing and medical care.

The media

Some newspaper articles have postulated that the pathway is directly used to create free beds and to get rid of unwanted, sick patients. This is blatantly untrue. No doctor has trained to intentionally assist patients to die. As a profession we are wholly against physician-assisted suicide, (another contentious, but not un-related, subject). Our calling is to relieve suffering.

Other articles have voiced the concerns of families as described in the paragraphs above. In the most part, poor communication is to blame.

Summary

On the whole, I believe the Liverpool Care Pathway successfully promotes what it initially set out. i.e. appropriate care for all patients in the final days of a terminal illness, no matter where they be in the NHS. Criticisms are understandable and I am sure are occasionally justified. It is also limited by a lack of data to prove its efficacy in improving the quality of patients' deaths. There are no randomized control trials to support its use, in an era of evidence-based medicine.

For it to be more widely accepted and used as intended it is clear that communication with patients and family is key.

So, within the context of certain clear limitations, I believe to allow the aims of the pathway to be achieved in terms of location, location, location, I would say that we need communication, communication, and communication.

References

1. Liverpool Care Pathway <http://www.liv.ac.uk/mcpcil/liverpool-care-pathway/documentation-lcp/>
2. Gold Standard Framework
http://www.goldstandardsframework.org.uk/About_GSF/WhyIsItImportant
3. NICE quality statement 13 <http://publications.nice.org.uk/quality-standard-for-end-of-life-care-for-adults-qs13>
4. www.scotland.gov.uk/Publications/2011/01/27090834/0 - 27 Jan 2011 and <http://www.scotland.gov.uk/Publications/2011/01/27090834/2>
5. Prof P Pullicino address to Royal Soc Medicine, as quoted in Daily Mail 20th June 2012 <http://www.dailymail.co.uk/news/article-2161869/Top-doctors-chilling-claim-The-NHS-kills-130-000-elderly-patients-year.html>