Snapshot Review of Complaints in End of Life Care
Key findings

There are few complaints made by bereaved relatives for patients who died in hospital (3 to 7 per cent of all complaints). Even fewer complaints have the Liverpool Care Pathway for the Dying Patient (LCP) as a contributing factor to the complaint.

Our analysis of 255 complaints for patients who died in hospital found little difference in the frequency of contributing factors to complaints between patients who received care supported by the LCP and those where care was not supported by the LCP (or this was unknown). Where there were differences these were associated with awareness of approaching end of life and meeting preferences / expectations of care.

There is a consistency of themes in our analysis with other reviews of complaints in end of life care. These themes include:

- awareness of approaching end of life
- communication and being caring
- symptom management (including pain)
- the environment
- concerns around clinical care, including withdrawal of treatment
- fundamental medical and nursing care.

The review also identified complaints about care leading up to transitions to palliative care from curative treatment that could be described as complaints about patient safety.

Our conclusion is that the analysis of complaints revealed a number of concerns about end of life care in acute hospital trusts, but few are specific to the LCP.

It is important to have a good overview of complaints about end of life care, alongside other patient, relative and staff concerns. In order to achieve this complaint information systems need the capability to code for end of life care. There may be benefits for hospital Trusts to align their overview of end of life care complaints with complaints about patient safety aimed at reducing serious avoidable harm and deaths, as complaints for someone who died can overlap these topics.

There are a number of ways hospital Trusts are enabling improvements to the quality of care alongside a strong governance of complaints and associated actions. This includes: developing real-time feedback to staff from relatives / patients so aspects of care can be adjusted, service transformation, and staff training and education.

Commissioned by the National Independent Review Panel of the Liverpool Care Pathway for the Dying Patient (LCP) for delivery by the former National End of Life Care Programme (now under the auspices of NHS Improving Quality).

June 2013

Snapshot Review of Complaints in End of Life Care

Summary

1. Background

The National Independent Review Panel of the Liverpool Care Pathway for the Dying Patient (LCP) commissioned the former National End of Life Care Programme (now under the auspices under NHS Improving Quality) to conduct a snapshot review of complaints in end of life care to:

- capture information on key themes and the proportion of complaints that relate to the LCP

- understand how hospital Trusts are learning from complaints and concerns in end of life care including pathways of care in the last hours / days.

The methodology was formally approved by the Review Panel in March 2013. The majority of the complaints reviewed were from the financial year 2011/12 to support a neutral position from the recent publicity around the LCP. The review started in March 2013 with 18 acute hospital Trusts agreeing to participate, 16 carrying out the review of recorded complaints and two supplying best practice examples.

2. Review of recorded complaints for people who died in hospital

The 16 hospital Trusts involved in this part of the review represent around 11% of English acute hospital Trusts and received 8,655 complaints in 2011/12. The participating hospital Trusts reviewed all or a sample of identified complaints[1], providing a total of 255 complaints. This snapshot review identified that between 3% and 7%[2] of all complaints received are for people who died in hospital.

Few complaints identified the LCP as a contributing factor (16 in total). Less than 30% of the 255 complaints reviewed were for people who were known to have received care supported by the LCP[3].

Our analysis of key themes and contributing factors focused on the following two questions:

1) What was the nature of issues where the LCP was identified as a contributing factor to the complaint?
2) Are there differences in the type of contributing factors in complaints for those where the patient was known to have received care supported by the LCP compared to those who did not or this was unknown?

2.1 The nature of the issues where LCP was identified as a contributing factor

The concerns raised in these 16 complaints included:

- Decision making and consent around the LCP, including timing of the initiation of the LCP

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[1] The interpretation of these categories may be subjective. For example it can be difficult to differentiate between complaints about the LCP versus a component of the LCP. We minimised the potential impact through the methodology and the dual analysis.
[2] Interquartile range
[3] 28% received care supported by the LCP, 64% did not, 8% this was unknown of the 255 complaints for people who died.

- Specific issues surrounding nutrition and hydration and use of artificial feeding, this can often relate to communication issues and understanding about aspects of care (eg relative perceives food and fluids were withdrawn, while the patient was receiving subcutaneous fluids)
- Poor adherence to specific aspects of clinical care set out in the LCP (eg overview of patient care, symptom management)
- Review of care for patients whose care is supported by the LCP for a long time or if a patient improves, and need for on-going communication and involvement with families
- Communication throughout: including initiation of the LCP and ensuring families are aware, understand and involved. There can be specific challenges where families are large and / or there are complex relationships and / or relatives live far away.

2.2 Comparing complaints for those who received care supported by the LCP and those that did not

The analysis of 255 complaints for patients who died in hospital found few differences in the frequency of contributing factors to complaints between patients who received care supported by the LCP and those where care was not supported by the LCP (or this was unknown).

We found there was a difference in three categories (Figure 1) of the 19 categories assessed. The LCP may enable families to be more aware their relative is approaching their last days of life but less likely to enable preferences of care or have aligned expectations of care. These two categories are inter-related as awareness is a prerequisite to enable preferences of care / clarifying expectations of care. The other area of difference is complaints relating to the LCP itself. From an analytical perspective we know this because the two black lines on the graph do not overlap, whereas the others do[4].

FIGURE 1

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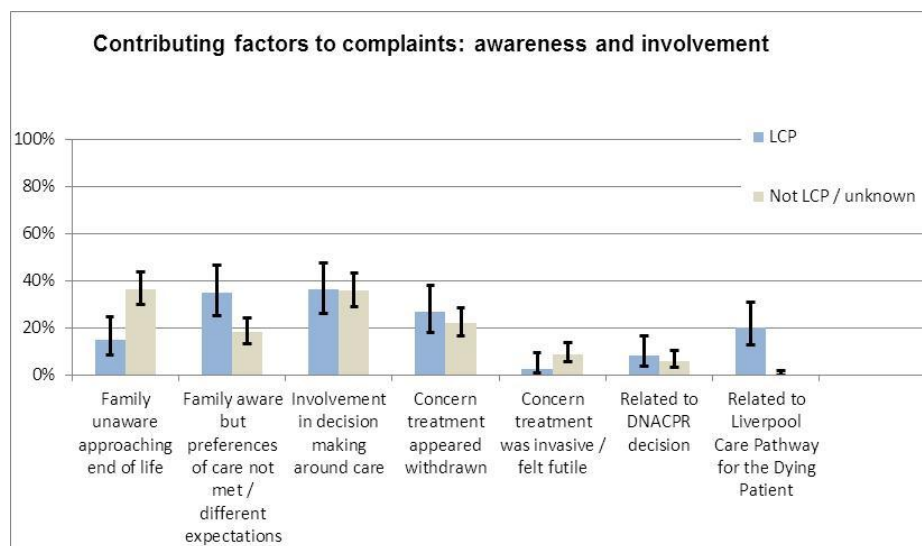
[4] This is a statistical analysis that takes into account small numbers when calculating percentages. Naturally you would have less confidence in saying there is a real difference between 5/10 and 6/10 compared to 500/1,000 and 600/1,000 though both are 50% compared to 60%. The black lines shown on the graph allows us to interpret differences in percentage using statistics to guide our interpretation. These black lines represent 95% confidence intervals.

Of the 19 different end of life care categories, 16 categories showed no difference between the two groups. The issues assessed include those shown in Figures 1 and 2 and the following other categories:

- problems with symptom management (eg pain management)
- too much medication (eg over sedation)
- problems with the environment for patients(not private enough or felt isolated)
- problems with the environment for relatives (not private enough or felt isolated)
- the number of times a patient was moved
- communication from or care from another provider
- complex family relationship from the perspective of the complainants

FIGURE 2

Contributing factors to complaints: communication
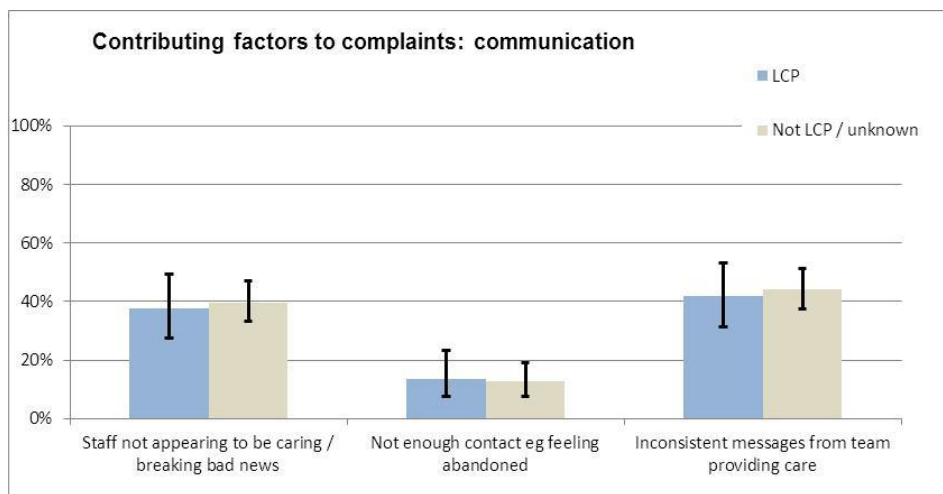
These topics are consistent with other reviews of complaints about end of life care. Our review also identified complaints about care leading up to transitions to palliative care. This may include issues about delays in diagnosis, referral, poor outcomes following interventions, and hospital acquired infections. These complaints could be described as complaints about patient safety. The other broad theme was about basic nursing and medical care (fundamental care) and new category 'cleanliness of the environment'. There were a small number of instances of complaints about patient safety and /or end of life care where relatives queried if the outcome could have been affected, for example if delays in diagnostic tests had not occurred.

The participating hospital Trusts were asked to comment on the impact of the media interest in the LCP on complaints. Our assessment is that there have been positives and negatives. The positive is that there have been more involved conversations with relatives. The label of "LCP" has empowered relatives to ask questions and have important conversations. The negative was highlighted by one hospital Trust where there has been a reduction in anticipatory prescribing of medication usually around symptom control and pain relief, associated with a drop in the use of the LCP.

Our conclusion is that the analysis of complaints revealed a number of concerns about end of life care in acute hospital Trusts, but few are specific to the LCP. Some of the complaints

we reviewed were complaints about fundamental care and patient safety. These broader themes sometimes overlapped and sometimes didn't.

3. How hospital Trusts learn from their overview of complaints and concerns

"Ensuring that people have a positive experience of care" is one of the key outcomes for the NHS in 2013/14 with the need to build capacity and capability for providers and commissioners to act on patient feedback[5]. Good end of life care is important as *'How people die remains in the memory of those who live on'*[6].

End of life care complaints provide valuable feedback about patients' care. All complaints for someone who died in hospital need review. This will include understanding causes, identifying appropriate actions, ensuring these actions take place and monitoring expected improvements. The types of improvements may be at an individual staff level, or may address hospital care systems, processes and /or staff training and development needs.

Hospital Trusts highlighted the need to code complaints as 'end of life care'. Complaints Information Systems need this capability, and hospital Trusts need an agreed process to consistently identify these complaints. One hospital Trust developed the following working definition which could enable an overview of complaints about fundamental care, patient safety alongside end of life care:

> *Any complaint relating to an admission where a patient died or where a patient died within 3 months of discharge.*

There may be benefits for hospitals to align their overview of end of life care complaints with complaints about patient safety aimed at reducing serious avoidable harm and deaths as the underlying issues can overlap when the complaint is for someone who died.

The innovation, knowledge and expertise already exist in the NHS to develop effective systems to overview of complaints about end of life care and enable improvement. This knowledge may need to be shared across the wider NHS system. The following represents our synthesis of best practice.

Alignments of incident reporting for end of life care patients with mortality overview
- Staff incident reporting around patients who die in hospital are a valuable source of information
- A complaint for someone who dies in hospital or soon after discharge and /or an incident reported about their care represent important information and these should be aligned
- There may be benefits to aligning this overview with hospital trusts mortality review meetings

Ensure there is a broader focus that includes concerns and compliments about end of life care
- Complaints and incidence may not reflect the prevalence of underlying problems
- They can be reinforced with other sources of intelligence patient, relative and staff experience of end of life care

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[5] http://www.england.nhs.uk/everyonecounts/
[6] Dame Cicely Saunders. Quote from the front of the National End of Life Care Strategy July 2008.

- A number of different approaches exist and work well: bereavement surveys, real-time patient feedback, real-time family feedback, casefile audits and other feedback loops, these can be informal as well as formal
- Aligning this overview enables clear prioritisation to support service improvement
- Establishing measurement systems that can demonstrate changes made are an improvement will demonstrate effectiveness of service improvement initiatives

Some changes reflect substantial cultural change and need for transformation
- There are multiple approaches to enable improvements
- Real time feedback loops to staff using 'relative diaries' will enable immediate adjustments to care as necessary. These need careful implementation as can reflect substantial cultural change and change in day to day practice.
- There are a number of proven service improvement methodologies to support change.
- One of these is the existing Transforming End of Life Care for Acute Hospitals Programme[7] .This provides an existing framework for improvement: strategy, training and education, overview and measurement with a focus on key enablers that support change in clinical practice[8].
- Innovative projects includes extending the role of the bereavement service to support bereaved relatives; hospital wide improvement initiatives in communication and patient experience; establishing clear clinical leadership with specialist palliative care teams.

4. Complaints handling for complainants who are bereaved.

There are a number of standards for complaints handling developed by the Patients' Association. Complainants who are bereaved have specific needs[9,10]. Knowing who is bereaved is a starting point. The other considerations are:

- Aim is to ensure bereaved complainants are dealt with compassion, dignity and respect
- Ensure there is someone who is skilled at dealing with distress and able to access bereavement support as needed. This expertise already exists in hospital Trusts
- Ensure apologies are conveyed in an appropriate language with sincerity and tact[11], a potential starting point is to review letters sent out to people who are bereaved
- Develop close links between the complaint teams / PALS and palliative care teams.

One hospital Trust highlighted that in their experience complaints are resolved more quickly through a meeting with bereaved complainants and senior clinicians involved in their relative's care. Their experience suggests that it is not easy to address concerns and distress in a written formal response.

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[7] http://www.endoflifecare.nhs.uk/search-resources/transforming-end-of-life-care-in-acute-hospitals.aspx
[8] 25 hospitals trusts from Sept 2011, 36 hospitals joined April 2013.
[9] Lowson, S. Why families complain about end-of-life care in the NHS. End of Life Care. 2007. 1(2)
[10] Francis, R. Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry Volume 1: Analysis of evidence and lessons learned (part 1). 2013
[11] Parliamentary and Health Service Ombudsman. The NHS hospital complaints system: A case for urgent treatment? 2013. London

5. Summary

In conclusion the analysis of complaints revealed a number of concerns about end of life care in acute hospital trusts, but few are specific to the LCP. There is a consistency of the themes highlighted in this review with other reviews of complaints in end of life care.

Complaints provide important feedback about bereaved relative's perspectives of the care a patient received. Therefore it is important to review these complaints alongside other sources of information. There may be benefits for hospital Trusts to align their overview of end of life care complaints with complaints about patient safety.

Complainants who are bereaved may have specific needs, including communication and support needs.