

Factors affecting the successful implementation and sustainability of the Liverpool Care Pathway for dying patients: a realist evaluation

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Received 9 June 2014

Revised 1 October 2014

Accepted 27 October 2014

Published Online First

7 November 2014

ABSTRACT

Objectives The Liverpool Care Pathway (LCP) for the dying patient was designed to improve end-of-life care in generalist healthcare settings. Controversy has led to its withdrawal in some jurisdictions. The main objective of this research was to identify the influences that facilitated or hindered successful LCP implementation.

Method An organisational case study using realist evaluation in one health and social care trust in Northern Ireland. Two rounds of semistructured interviews were conducted with two policymakers and 22 participants with experience and/or involvement in management of the LCP during 2011 and 2012.

Results Key resource inputs included facilitation with a view to maintaining LCP 'visibility', reducing anxiety among nurses and increasing their confidence regarding the delivery of end-of-life care; and nurse and medical education designed to increase professional self-efficacy, and reduce misuse and misunderstanding of the LCP. Key enabling contexts were consistent senior management support; ongoing education and training tailored to the needs of each professional group; and an organisational cultural change in the hospital setting that encompassed end-of-life care.

Conclusions There is a need to appreciate the organisationally complex nature of intervening to improve end-of-life care. Successful implementation of evidence-based interventions for end-of-life care requires commitment to planning, training and ongoing review that takes account of different perspectives, institutional hierarchies and relationships, and the educational needs of professional disciplines. There is a need also to recognise that medical consultants require particular support in their role as gatekeepers and as a lead communication channel with patients and their relatives.

BACKGROUND

More than a decade ago Ellershaw and Wilkinson¹ proposed that the hospice philosophy of care for the dying could be transferred to other settings, including acute hospitals and nursing homes, through implementation of the Liverpool Care Pathway (LCP), a continuous quality improvement programme. The LCP was subsequently recognised as an important tool for improving best practice in end-of-life care² recommended for use in all care settings by the End of Life Care Strategy in England³ and subsequently in other jurisdictions, including Northern Ireland.⁴

However, the Neuberger review in July 2013 concluded that use of the LCP was too often associated with poor care. It cast doubt on the suitability of the pathway approach and criticised the manner in which it had been implemented.⁵ Based on that report, the LCP has been replaced in England by individualised end-of-life care planning. Even so, simply withdrawing the LCP and replacing it with an end-of-life care plan and condition-specific guidance—a recipe that has not been prospectively evaluated—will not necessarily improve end-of-life care.⁶ There remains a need for a stronger evidence base for the components as well as the implementation of end-of-life care planning.⁷ This study aims to strengthen the evidence base with respect to implementation by identifying the factors that facilitated or hindered the implementation of the LCP in order to provide evidence to support the introduction of effective and acceptable approaches to end-of-life care. We address two questions: (1) what mechanisms facilitated the implementation of the LCP? (2) what



To cite: McConnell T, O'Halloran P, Donnelly M, et al. *BMJ Supportive & Palliative Care* 2015;5:70–77.

contextual factors influenced the effects of those mechanisms?

METHODS

Realist evaluation (RE) examines the processes that mediate the effects of an intervention on outcomes.⁸ Rather than merely asking ‘what works?’, RE asks ‘what works, for whom, in what circumstances?’.⁹ It rejects unilinear conceptions of the causal relationship between intervention and outcomes, instead regarding causal mechanisms as multiple and interactive, with particular outcomes being the result of their combination and interaction in a given context. Programme mechanisms embedded in an intervention can be understood as the inducements, sanctions, reasons and resources offered by a programme designed to change people’s behaviour to support a specific goal. The influence of these mechanisms cannot be predicted in isolation but depend on the context into which they are implemented, which will contain numerous extraneous social mechanisms. The central aim is to provide information that will enable decision-makers to judge whether the lessons learnt could be applied in other settings.¹⁰

Design

The study was an organisational case study of the implementation and sustainability of the LCP within one health and social care trust in Northern Ireland. It attended to outcomes and also the social processes that led to those outcomes.¹¹ Greenhalgh *et al*’s¹² model for the diffusion of innovations in health service organisations was used as an analytic framework to guide data collection and analysis.

Setting

The Trust treats approximately 210 000 inpatient and day patients per year,¹³ with approximately 1750 expected deaths per year.¹⁴ Health service participants were drawn from two service groups within the Trust; namely Cancer and Specialist Services, and Acute Services, with a focus on two hospital wards from each service group. These were deemed the most appropriate settings to explore LCP use based on their comparability in terms of the number of foreseen deaths and the proportion of those patients entering the LCP. Implementation of the LCP had been supported by a facilitator employed for 2 years (2005–2007) with funding from the Big Lottery Fund (the body responsible for delivering funds raised by the UK National Lottery). Following the expiry of external funding, the facilitator post was terminated. Another important feature of the setting was a major reorganisation of Northern Irish health services from 2007 onwards, which led to the amalgamation of trusts and many changes in managerial roles and personnel.

Participants

Twenty-two staff members from the two service groups and two policymakers from the Department of Health, Social Services and Public Safety, who had experience and/or involvement in management of the LCP, were recruited between 2011 and 2012. Sampling was purposive in order to achieve a wide range of key stakeholders. These included three palliative care consultants, three previous LCP facilitators, two service managers, four medical consultants, and four ward sisters, four staff nurses and two junior doctors. All participants were approached to participate via email.

Data collection and analysis

Two rounds of semistructured interviews were conducted at the participant’s work place. The primary purpose of the first round was to attain descriptive data about the use of LCP in the service areas involved. The interview guide was designed to integrate a broad opening question about the interviewee’s role in relation to the LCP, and a final question asking if there was anything further they would like to add in relation to the implementation of the LCP. These data were then used in conjunction with the findings in a review of the literature¹⁵ to formulate theories about the most salient influences involved in promoting or inhibiting the successful implementation and sustainability of the LCP in the service areas under study. The primary purpose of the second round of semistructured interviews was to present these theories to participants and discuss their validity and implications. Credibility was enhanced by ongoing interaction with the data during collection as well as during analysis, along with employing NVivo software to systematically manage and analyse the data. With participants’ consent, all interviews were audio recorded. Transcription was cross-checked for accuracy, and thematic analysis was conducted by two researchers. Initial codes and themes were developed from the review of the literature¹⁵ and Greenhalgh *et al*’s¹² model to strengthen analytic generalisation. Analytical rigour was strengthened by using a constant comparison approach along with searching for negative cases when developing codes and themes.¹⁶ Reflexivity was maintained throughout by keeping memos in relation to emerging themes that were discussed with the research team.¹⁷ Final mechanisms and contextual factors were reviewed by the researchers and feedback was obtained from key stakeholders.

Ethical considerations

Anonymity and confidentiality were discussed with participants, and informed consent was obtained prior to each stage of data collection. The study was approved by the Office of Research Ethics Committees Northern Ireland and by University and HSC Trust Research Governance Offices.

RESULTS

The research identified key mechanisms that were crucial to the successful implementation and sustainability of the LCP. These were facilitation, education and training. Those familiar with the LCP will recognise that these are central components of the pathway. However, our research uncovered differentials in the effects of these components, in that they were perceived and valued differently by different stakeholder groups. We were also able to identify characteristics of the organisational context that had an impact on implementation and sustainability.

Facilitation

The role of the LCP facilitator was to market the pathway, deliver LCP education and training, and audit how often and well the LCP was being used. In congruence with findings from the literature review,¹⁵

interviewees felt that LCP facilitation was crucial to the launch and implementation of the LCP (box 1). The visibility of the LCP facilitator on the wards acted as a reminder for nursing staff to consider the LCP for patients at the end-of-life. Also, explanations about the background to the LCP and about how it could benefit patient care appeared to motivate staff to use the pathway when appropriate. Finally, support of clinical staff to make difficult decisions and change ingrained ways of working, such as identifying patients in an end-of-life phase and shifting their focus from active treatment to a more palliative approach reduced staff anxiety and increased their confidence to use the LCP.

Termination of the facilitator post had a pronounced negative impact. While nursing staff viewed palliative care consultants as a valuable resource for ongoing support and advice, those consultants felt they could

Box 1 Facilitation

Visibility mechanism: reminded staff to use the pathway

- ▶ "Yeah, it (facilitation) was vital, yes. I think the difference was also having a person who was visible, and who would have gone round to all the wards to make sure that even their presence was enough to remind people, yes, the pathway." (Palliative care consultant)
- ▶ "So I think that was a big thing when they pulled the facilitator post at the end of the project. Out of sight out of mind." (Facilitator)

Supportive mechanism: reduced anxiety and increased confidence among nursing staff

- ▶ "And the big one that I always talked about was the two hourly turns, because in nursing you were nearly ingrained to turn patients two hourly. And you went in and you just turned people. And sometimes you turned them and they died. And it was all that sort of thing about reassuring nurses that you don't feel, not to feel guilty. You nearly feel as if you have to do something. So again it was that getting across that need. It's not your need as a nurse that you need to go in and turn the person to make you feel better." (Facilitator)
- ▶ "But definitely at the start having that person to drive it, and implement it. And to answer queries and concerns. Help iron out any problems that we were having with it. That was definitely very helpful." (Ward sister)

Contextual barrier: scarce resources

- ▶ "So what do you want ... our team ... not to do? So do you want our nurses (specialist palliative care nurses) not to see patients on the wards for a week, two weeks or three weeks? So what is going to be given up? And of course if we do that we'll have a waiting list which then becomes an issue. Why is this patient not going home? Because the palliative care team haven't seen them yet. So it's all very tangled ... whereas perhaps any other business if you wanted to introduce something you wouldn't try to do it within existing resources. You'd say, 'Actually we need to invest in this. This is something we believe in. We need to invest time, effort and money.'" (Palliative care consultant)

Contextual barrier: differing needs and expectations

- ▶ "It's still in operation, and whenever we see a patient for whom the pathway would be suitable we will bring it forward and discuss it with our medical colleagues as being an appropriate direction for that person's care. And it is still being used and it's still ... worthwhile." (Staff nurse)
- ▶ "I suppose ... in the absence of a facilitator for the project, to say it was dying a death is probably a bit strong, but ... we knew as a team it wasn't being sustained in the way that it had been originally when there were people supporting it." (Palliative care consultant)
- ▶ "I think wearing a commissioning hat I expected that ... the Trust would make sure that they had the systems and processes to ensure ongoing training, quality, implementation and so on, but in fact once the facilitator went the ownership of that was not, and the responsibility was not properly sorted. So the job of implementation should have included not just actually doing and training and getting people involved and raising awareness but it also should have involved a whole systems and planning approach and it didn't. Well I presume it didn't because it fell down once people had left and I suppose one of my worries was maybe the implementation was just never as wholesale as it might have been." (Policymaker)

not provide adequate support in the context of rapid staff turnover and competing demands.

It was also apparent in reports from different stakeholders that the impact of facilitation was perceived differently depending on their needs and expectations. Nurses who worked on wards that were using the LCP believed that the facilitators had successfully embedded the pathway into practice and that the pathway remained an effective part of patient care once the facilitator post had ended. On the other hand, the palliative care consultants who worked across wards and departments felt the LCP was not being sustained in the way it had when a facilitator was in post. Furthermore, policymakers who were aware of regional audit data showing a significant number of potentially eligible patients who were not offered the LCP thought that the pathway had not been sustained.

Education and training

At the implementation stage, LCP education was delivered to nursing and medical staff by the LCP facilitator. The Palliative Care Team also had a key supportive role in relation to issues such as symptom management, spiritual and psychological aspects of care. The LCP facilitator reported that senior management support for education and training helped ensure that all staff had an understanding of how to use the pathway effectively and appropriately (box 2). However, although the education on offer was valued by nurses and junior medical staff, who felt better equipped and more confident to deliver end-of-life care, there was some evidence that medical consultants were sceptical of the pathway approach, and so did not think training should focus on the LCP. Rather, they valued more general training in palliative care, with the LCP as one of the available tools.

Box 2 Education and training

Self-efficacy mechanism

- ▶ “And so by doing the teaching sessions on the ward you were able to gather a feel of, is there anything about this that’s frightening the nurses, or is there anything that they’re not happy about, or anything that they’re not sure of.” (Facilitator)
- ▶ “I think it (education and training) definitely helps. I think it’s quite a scary thing, the pathway. You know, at the start for, the first time you use it.” (Junior doctor)

Facilitative context: senior management support

- ▶ “Because it was seen that this implementation process had to happen I did have the beauty or luxury of having senior management say this was happening. All the staff need to be attending (education sessions). It was seen as mandatory. Although it wasn’t mandatory it was seen as mandatory.” (Facilitator)

Contextual barrier: Medical ambivalence toward pathway approach

- ▶ “What is important is that people who are dying are looked after in a caring, professional and effective way. Simply being on a care pathway doesn’t ensure you get best care.” (Medical consultant)
- ▶ “I think that mandatory training has its dangers in that there are a lot of things that are mandatory and pitched at totally the wrong level. I think it would need to be as part of more holistic end-of-life training ... parcelled in with clinical palliative care or legal and ethical aspects of end-of-life care...It would need to be some meaningful training rather than a half afternoon looking at the pathway. That I think would just really engender ‘antibodies’ rather than anything else. It would need to be something I felt ... a precious afternoon’s two hours clinical time was worth it.” (Medical consultant)

Contextual barriers: Lack of ongoing senior management support and withdrawal of facilitators

- ▶ “So instead of being driven by us it should be driven by the clinical governance group and it should be their priority to drive it. Because it doesn’t work when we are driving it if the Trust Governance isn’t interested.” (Palliative care consultant)
- ▶ “It’s not just implementation really. The ideal would be to have somebody in post, not only to implement but see the whole process through and continue with the training and education for it because there’s going to be new staff turnover. So it’s a constant not just implementation.” (Palliative care consultant)

Negative outcomes: misuse and misunderstanding

- ▶ “I don’t know how well people are familiar with it. I know it has been used inappropriately many, many times, because for example, certain individuals like the guidance at the back of it. So they use the pathway because they like the guidance but it’s not really appropriate because the patient isn’t in the last hours or days of life. And if patients are on it for a long period of time then it needs to be reviewed. That’s not happening. So, I’m not sure that people out there are fully aware of how to use it appropriately.” (Palliative care consultant)
- ▶ “I think it’s 95% about education ... as to the fact that this is not a euthanasia tool. It is a map for good care.” (Palliative care consultant)

Furthermore, with waning senior management support and withdrawal of a dedicated LCP facilitator, education and training were delivered informally to new staff by nurses on the ward and by the palliative care consultants when available. This led to much frustration for palliative care consultants who felt education was key to successful implementation and sustainability. For example, palliative care consultants reported misuse and misunderstanding of the LCP on some occasions. Misunderstanding in terms of what the pathway was intended to do, namely guide generalist staff to deliver the best end-of-life care, rather than deprive patients of care, and misuse through initiating the LCP too soon and without regular review.

Audit and feedback

Organisational and clinical data for the National LCP audit were collected biennially from each hospital trust using the LCP. These results were then analysed by the LCP Central Team, which provided support and information regarding the LCP, after which each participating hospital received a full individual report of their performance alongside that of the whole sample.¹⁸

Our review of the literature¹⁵ suggested that formal audit and feedback were key drivers for the implementation of the LCP. However, this did not figure strongly in the reports of participants as having an impact on the sustainability of the LCP. Few outside the palliative care team seemed aware of audit results. However, other forms of feedback were valued by professionals (box 3). For nursing staff, it was the usefulness of the

LCP in individual practice that generated motivation to use the pathway. Similarly, interview data from medical consultants suggested that positive peer influence and seeing the benefits of practice change in relation to good nursing care, patient comfort and family contentment were more likely to encourage their involvement with the pathway.

Context: organisational and social issues

One of the important insights of realist approaches to evaluation is the acceptance that there is no simple relation of cause and effect between a mechanism and its outcome. Outcomes will depend on the interaction of mechanisms with each other and with the organisational context in which they are used. Thus, while facilitation, education and feedback were important, their impact was mediated by the context in which they were implemented.

A number of organisational and social barriers to the sustainability of the LCP were identified by participants. These included inter-professional relations, negative public perceptions of the LCP, lack of organisational commitment and scarce resources.

Professionals were of course thinking about end-of-life care before the advent of the LCP, so their approach to the LCP was very much affected by how they saw their role at the end of a patient's life. As might be expected, attitudes varied between and within professional groups. Generally speaking, nurses were active in promoting use of the LCP, while on the medical side palliative care consultants were advocates, medical consultants ambivalent, sometimes sceptical and junior doctors' attitudes were very much dependent on the approach of their seniors. In this trust, medical consultants were the gatekeepers to the LCP and had the final decision as to whether it would be used for a given patient. While this could be seen as good practice in that a senior experienced professional was making the decision it could also lead to frustration for other members of the team if a consultant was reluctant to use or even consider the pathway (box 4).

The medical consultants themselves identified their focus on cure and an antipathy to the pathway approach as attitudes that made them less likely to use the pathway. However, they also identified a further difficulty: the perception among some members of the public that the LCP was a 'pathway to death' and so a sign to relatives and patients that the medical team was abandoning the patient. Some consultants responded by taking the steps recommended by the LCP without using the official document.

A range of participants reported that organisational commitment to the LCP was lacking, as evidenced by the invisibility of the pathway in clinical governance terms. This lack of engagement appeared to be a function of the large size of the organisation (the two service groups alone contained more than 8000 staff),

Box 3 Audit and feedback

Motivational mechanism: nursing staff—streamlined care

► "It was actually the staff came to me because they felt that there were very good prompts. So it meant care, you know, they weren't wasting time writing reams about mouth care, or reams about other things. So they felt that the guide and the pathway documentation actually streamlined care and made it very simplistic." (Facilitator)

Motivational mechanism: Medical consultants—'seeing' the benefits more motivating than audit results

► "I think having someone who is an exemplar is important. And that has a sort of ripple effect ... if you can see that the patient's peaceful and that the family ... are as contented as can be in the circumstances, and you know that good nursing care is being delivered, I think that is positive feedback. So you can get National figures and audit it locally but there is a satisfaction in seeing someone and their family peaceful and prepared as opposed to fraught and anxious." (Medical consultant)

Box 4 Context: professional, organisational and social barriers

Inter-professional relations

- ▶ "If consultants don't want to use it (the LCP) you can't force them to ... The consultants are independent practitioners so if they feel that the pathway doesn't help in improving the care of their patients for whatever reason then they may not be keen to use it." (Palliative care consultant)
- ▶ "If you've a consultant for whatever reason can be stubborn about these things then they won't get implemented ... no matter how much I as a ward sister or any nurse will shout and scream and stamp her feet. It won't happen. And that's the reality of it." (Ward sister)

Medical Consultants' Professional Ideologies: culture of cure and antipathy toward pathway approaches to care

- ▶ "Problems initiating the pathway are more related to a perception that medical staff are involved in healing the sick rather than managing death." (Medical consultant)
- ▶ "Clinicians don't like pathways, and if they aren't involved in the process there's the temptation to back off ... This is in part because of fear it can result in formulaic, lowest common denominator medicine, without due thought as to what is going on in a particular case. This opposition can be entrenched even if there is good evidence, for example, with the WHO surgical checklist. Nursing staff are often better at following pathways than doctors. Perhaps again a matter of professional culture." (Medical consultant)

Social barriers: negative public perceptions in response to negative media

- ▶ "I have had family members plead with me not to put their relative on the pathway. In some cases I have implemented the features of the pathway, but not the formal documentation so as to avoid this." (Medical consultant)

Organisational barriers: lack of organisational commitment, large scale organisational change and lack of ongoing resources focused on sustaining LCP

- ▶ "So instead of being driven by us it should be driven by the clinical governance group and it should be their priority to drive it. Because it doesn't work when we are driving it if the Trust Governance isn't interested. And I think we've all kind of learnt that if driven by us it's not going to succeed. And we don't have the say and the influence for it to work." (Palliative care consultant)
- ▶ "I think it probably was affected by ... reorganisation ... Certainly I know that many of the people in jobs changed. I don't mean clinical staff, I mean managerial staff, and I know a number of the agreed processes and systems that had been set up before (re-organisation), it was difficult to maintain those during the process of change. There were lots of structural and managerial changes. So I think that was probably one of the many issues in terms of sustained implementation of it as well ..." (Policymaker)
- ▶ "I mean resources are so tight at the minute... and we obviously then have to prioritise our training. There's no formal Liverpool Care Pathway training that I'm aware of." (Ward sister)

the high number of initiatives vying for attention and the effects of the recent reorganisation on management continuity.

DISCUSSION

One of the advantages of RE is that it widens the focus of evaluation beyond the specifics of the intervention being examined to the broader considerations about what needs to be in place to promote its successful implementation and sustainability. The key findings of this research indicate that this depends on a complex matrix of facilitation, education, training and context.

Facilitation is recognised as an important resource input for supporting and increasing the likelihood that new innovations will be successfully implemented.^{19 20} Our findings indicated that facilitation also maintained 'visibility' of the pathway.¹⁹ Unlike medical and nursing charts, which are highly visible and used as part of everyday routine practice, LCP documentation is kept separately and relies on staff remembering to use it. This finding was consistent

with previous research showing that unless care pathways were visible and accessible, they were rarely used.²¹

Policymakers had assumed that the use of LCP facilitators within a limited funding period would be sufficient to sustain the programme. However, interview data suggest that success depends not only on facilitation skills but also on the level and consistency of support at senior management level for sustaining key structures and processes¹² such as education and training.

Moreover, if programme implementers do not tailor their approach for different groups of professionals within the multidisciplinary team, they may alienate certain groups such as senior medical staff. Medical consultants are more likely to be involved with education and training that they see as meaningful and worthwhile. More rounded education and training on palliative and end-of-life care was seen to be of greater value to their practice than focusing on how to complete the LCP documentation. Furthermore, lack of general knowledge of palliative care may lead

to inappropriate use of the pathway for patients who are in a palliative rather than end-of-life phase.

It was surprising that only medical consultants mentioned their reluctance to use the LCP (or to be seen to do so) in the face of opposition or misunderstanding among relatives of dying patients. We can only assume it was more pertinent to medical consultants who were on the front line in terms of decision making for patients who were in the last hours or days of life. Perhaps counterintuitively no other professional groups mentioned this societal context as affecting their approach to the LCP.

Contrary to our literature review's¹⁵ conclusion about the effectiveness of audits, the results of national and local audit seemed to hold little interest for those outside the specialist palliative care team. This may be because the key supporting structures for effective feedback and action were not in place. Consonant with previous research this indicates the need for appropriate investment in the infrastructure and resources required to support a pathway approach.²¹ However, several authors suggest peer influence and having a positive opinion leader are key motivating factors for successful adoption of innovations among medical consultants.^{22 23} This study indicates that medical consultants do value this more tangible feedback on improved patient care over more abstract audit results.

Previous research indicates that programmes addressing wider policy issues will attract more commitment from senior management²⁴ and therefore the resources to sustain them.²¹ However, although the LCP addressed the policy agenda to improve end-of-life care, resources were an ongoing area of contention in this study. This highlights the need for health service managers to ensure that higher policy level decisions are comprehensively translated into organisations' core business.

Some of the findings from this research echoed the implementation issues and limitations of the LCP uncovered in the Neuberger review.⁵ They reinforce Sleeman and Collis's⁶ identification of the need for a stronger evidence base for end-of-life care tools to avoid making the same mistakes again and also highlight the pitfalls to avoid when implementing end-of-life care guidance. As such, our study will be of interest not only to those seeking to understand the weaknesses of the LCP but also to those charged with introducing similar processes in the same contexts.

Strengths and limitations

This research involved a single case study because of organisational changes which resulted in the amalgamation of Hospital Trusts. Some advocates of the RE approach would view this as a weakness, recommending comparisons across different organisations.¹² However, other researchers view use of a single case study as a strength and have used the approach successfully in a single setting.⁸ Moreover, the theoretical

insights gained from our literature review¹⁵ further complement and strengthen the transferability of our findings.

CONCLUSION AND RECOMMENDATIONS

It is evident that simply ensuring that key processes (facilitation, education and training) are in place, though necessary, is insufficient to guarantee successful implementation. Healthcare organisations are complex, multiprofessional and hierarchical, with many competing priorities for resources. For an intervention such as the LCP—or its replacement—to succeed it must not only be enshrined in policy but enjoy significant organisational support. Healthcare organisations should make end-of-life interventions a valued part of clinical governance arrangements; and ensure a common understanding of the plan for implementing and embedding the intervention, with a level and timescale of funding appropriate to the size and complexity of the organisation.

Those planning the implementation of interventions such as individualised end-of-life care plans should consider the differing perspectives and educational needs of the professional groups involved; and how interprofessional and intraprofessional communication processes can thrive in the hierarchical world of clinical decision-making. Given the crucial role of medical consultants as gatekeepers for the intervention and their difficult role in having to make end-of-life decisions and explain these to patients and their relatives, this is a group that should attract special attention and support in relation to communicating effectively with colleagues, patients and their relatives.

However, a focus on implementation is not on its own enough to ensure effective end-of-life care. This research only provides evidence in respect to one side of the coin. What is now needed is robust research to evaluate patient and family experience of care and the dying process⁷ so that the lessons learnt from process evaluations such as this can be used to guide implementation of interventions with a strong evidence base for improved end-of-life care. Finally, there is a role for policymakers, politicians and opinion leaders in increasing public understanding of end-of-life decision-making so that healthcare professionals are not operating in a climate of fear and misunderstanding.

Acknowledgements The authors would like to acknowledge the Centre for Health Improvement, Queen's University Belfast as the funding source for this research; Queen's University Belfast and the Belfast Health and Social Care Trust as co-sponsors; the two Service Groups within the Trust, Cancer and Specialist Services and Acute Services, which provided access to research participants; and the staff nurses, ward sisters, LCP facilitators, junior doctors, medical consultants, palliative care consultants, service managers and policymakers who consented to participate in the research.

Contributors TM and PO were primarily responsible for the design and development of the research; all data were collected by TMC, who also undertook initial analysis and wrote the first

draft of the manuscript. Coauthors, PO, MD and SP contributed to conceptualisation of the paper, critique of the analysis and synopsis of findings. All provided editorial contributions and approved the final version of the manuscript.

Funding TM was supported during this work by a research studentship from the Centre for Health Improvement, Queen's University Belfast.

Competing interests None.

Ethics approval The study was approved by the Office of Research Ethics Committees Northern Ireland and by University and Health and Social Care Trust Research Governance Offices.

Provenance and peer review Not commissioned; externally peer reviewed.

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