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'It doesn't do the care for you': a qualitative study of health care professionals' perceptions of the benefits and harms of integrated care pathways for end of life care

Journal:	*BMJ Open*
Manuscript ID:	bmjopen-2015-008242
Article Type:	Research
Date Submitted by the Author:	19-Mar-2015
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Primary Subject Heading:	Palliative care
Secondary Subject Heading:	Palliative care, Health policy, Qualitative research
Keywords:	Adult palliative care < PALLIATIVE CARE, GENERAL MEDICINE (see Internal Medicine), Health policy < HEALTH SERVICES ADMINISTRATION & MANAGEMENT

'It doesn't do the care for you': a qualitative study of health care professionals' perceptions of the benefits and harms of integrated care pathways for end of life care

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Objectives: To understand health care professionals' perceptions of the benefits and potential harms of integrated care pathways for end of life care, and to inform the development of future interventions that aim to improve care of the dying.

Design: Qualitative interview study with maximum variation sampling and thematic analysis.

Participants: 25 health care professionals including doctors, nurses and allied health professionals, interviewed in 2009.

Setting: A 950 bed South London teaching hospital.

Results: Four main themes emerged, each including two sub-themes. Participants were divided between those who described mainly (i) benefits of integrated care pathways, and those who talked about (ii) potential harms. Benefits focused on processes of care, e.g. clearer, consistent, and comprehensive actions. The recipients of these benefits were staff members themselves, particularly juniors. For others, this perceived clarity was interpreted as of potential harm to patients, where over-reliance on paperwork lead to prescriptive, less thoughtful care, and an absolution from decision-making. Independent of their effects on patient care, integrated care pathways for dying had a (iii) symbolic value: they legitimised death as a potential outcome and were used as a signal that the focus of care had changed. However, (iv) weak infrastructure including scanty education and training in end of life care and a poor evidence base, appeared to undermine the foundations on which the Liverpool Care Pathway was built.

Conclusions: The potential harms of integrated care pathways for dying identified in this study were reminiscent of criticisms subsequently published by the Neuberger review. These data highlight: (i) the importance of collecting qualitative data when developing and evaluating complex interventions; (ii) that comprehensive education and training in palliative care is critical for the success of any new

intervention; (iii) the need for future interventions to be grounded in patient-centred outcomes, not just processes of care.

Strengths and limitations

Integrated care pathways for end of life care have been the subject of considerable media and political scrutiny, but research scrutiny has been lacking. This in depth qualitative study examines health care professionals' perceptions of the benefits and harms of integrated care pathways for end of life care in order to inform the development of interventions to improve care for the dying.

We interviewed health care professionals from different grades and within medical, surgical and allied specialties, and have developed detailed insights into the factors associated with successful implementation of integrated care pathways for end of life care.

By using data collected in 2009, we are able to understand the views of health care professionals in the period before the media controversy and Neuberger review.

We interviewed a disproportionately large number of staff members from the Intensive Care Unit, and participants were from a single tertiary referral centre, which may not be representative of the wider clinical setting.

Introduction

The Liverpool Care Pathway for the Dying Patient (LCP), an integrated care pathway for end of life care, was developed in England in the late 1990s.[1] It aimed to distil the most important elements of good end of life care from the hospice setting, and transform them into a series of prompts to guide and improve care in hospitals and across community settings. The LCP was rapidly suggested as a model of good practice by the UK Department of Health and it formed an integral part of the National End of Life Care Programme.[2] The LCP (or modified versions of it) was subsequently introduced in the United States, Australia, China and Europe.[3]

The aim of any integrated care pathway is to improve patient outcomes by promoting consistency and streamlining processes of care.[4] Although there was evidence that the LCP improved processes of care, for example anticipatory prescribing of drugs for symptom control, prospective evidence of its benefits to patient outcomes, for example improvement in symptoms, was lacking.[5,6] In 2013, following intense media scrutiny in the British press of its potential harms, an Independent Review led by Baroness Neuberger identified numerous accounts of poor care associated with the Liverpool Care Pathway and concluded that, in the absence of reliable evidence of the pathway's benefits,[6] its use could no longer be justified.[7]

The extent to which health care professionals were aware of and in agreement with the potential harms exposed by the media and Neuberger review is unclear. Health care professionals' views around the LCP were studied prior to the Neuberger review, but these studies cited mainly positive attitudes towards the impact of the LCP on the processes of care, for example improvement in communication, continuity, documentation, and as an educational tool.[8-11] None cited harms similar to those reported in the Neuberger review. However, these studies were limited in terms of the population included.

Understanding the a priori reservations of health care professionals regarding potential harms of integrated care pathways for end of life care would help inform the implementation of the LCP outside the UK where it is still being used,[12] and the development of any future interventions to improve care of the dying. We analysed data collected in 2009 as part of a mixed methods study to develop and implement a tool to improve palliative and end of life care in Intensive Care Units (ICUs).[13] The original study collected data on the perceptions of health care professionals towards integrated care pathways for end of life care, including the LCP. The data were collected long before the issues were raised strongly in the British press and four years before the Neuberger review reported. One of the aims of the original study was to explore the views expressed by professionals about the potential benefits and harms of care pathways at the end of life. The findings are presented here, and compared to those issues subsequently identified by the Neuberger review.

Methods

Design

This was a qualitative analysis of interviews with health care professionals. The data were collected as part of a study which followed the MRC framework and MORECare statement of methods,[14] to develop and assess a tool to improve palliative and end of life care in ICU. The original study and the results are published elsewhere.[13]_The study was granted ethical approval by the South East London REC (08/H0805/65 and 08/H808/103) and received full hospital Research and Development approval.

Setting

Two adult ICUs in a 950 bed South London teaching hospital, serving an area characterised by social deprivation and culturally and ethnically heterogeneous populations.

Participants

Maximum variation sampling was used to select potential staff participants to gain perspectives from a broad range of health care professionals, taking into account age, gender, profession and experience, and included both ICU and other hospital staff. Staff were recruited purposively, identified through discussion with key staff members, and approached by letter or email. Written informed consent was gained from each participant prior to interview. 25 participants were interviewed: 13 nurses (junior to senior), six ICU doctors (junior to senior), one transplant coordinator, two social workers, two senior physicians and one senior surgeon. Three participants had extensive palliative care experience. All participants had some familiarity with integrated care pathways for end of life care including the LCP, though experience varied by clinical setting and grade. Interviews were carried out in 2009.

Data collection

An interview time convenient to the healthcare professional was arranged (outside of clinical duties). Interviews were conducted in a confidential setting away from the clinical workplace unless the participant preferred not to. Interviews lasted 30-60 minutes and were conducted face to face with one of two trained interviewers (CS (MSc), a senior research fellow and an experienced qualitative researcher, with an interest in non-specialist provision of palliative care; CR (MD, MSc), a clinical research associate trained in qualitative methods). No relationship had been established prior to study commencement, and there were no non-participants present. Topic guides were developed from a literature review, initial observations and discussions with service users, and explored perceptions, recommendations and views on integrated care pathways for palliative and end of life care (including the LCP), processes of decision making, and experiences of palliative and end of life care. Questions were open-ended, and were piloted and revised. No repeat interviews were carried out. All interviews were digitally recorded and transcribed verbatim. The data were anonymised and code numbers allocated to each case. Themes were fed back and data was discussed with the project advisory group and with participants.

Analysis

We used thematic analysis to inductively identify patterns and themes within the data. This approach utilizes five related steps of: familiarisation, coding, theme development, defining themes and reporting.[15] All interview data were reviewed during the process of familiarization, and all sections of the interviews relating to the experience of utilizing integrated care pathways were extracted. Emergent themes were identified from the data, defined and reported through an iterative process of theme development.

The primary data coder was KES. Specialist software was not used. To address issues of analytical rigor and trustworthiness, a subset of transcripts were double-coded by KB. A re-iterant process of discussing areas of agreement and disagreement took place between KES and KB to achieve consensus. Alternative interpretations were incorporated in the analysis. The analysis was further tested during discussions with colleagues, and meetings of the project advisory steering group. We also paid attention to non-confirmatory cases where emerging themes contradicted more common ideas. Quotations were chosen to illustrate the themes, and to include a range of study participants.

Results

Four themes were identified from the interview transcripts, each including two sub-themes. Participants were divided between those who cited mainly benefits of integrated care pathways, and those who talked about potential harms. Integrated care pathways for dying appeared to have a symbolic value, which was independent of their effect on care provided to patients. Underlying this were comments relating to the context and infrastructure within which care was provided (Figure 1).

The benefits of integrated care pathways for the dying

Processes of care

Many participants cited benefits of integrated care pathways for dying with respect to processes of care. Staff, particularly the nursing staff, valued the structure that integrated care pathways provide, and there was frequent mention of improved clarity about the care which was to be provided.

'I think perhaps it does mean that everybody has a clear picture as to what we are doing and not doing.' (senior nurse)

Integrated care pathways were felt to make care of the dying more consistent and comprehensive, and were felt to be particularly valuable in situations where continuity was compromised, for example out of hours or when turnover of staff (medical or nursing) was high.

'The biggest challenge I find as a nurse is not really knowing where you stand sometimes with treatment with, you know, perhaps the weekend…that's why I think the pathway is a good thing because it gives people guidance and gives us nurses something to follow.' (senior nurse)

An extreme view was that integrated care pathways for end of life care could provide a substitute for verbal handover:

'So having a form …can make sure that everybody involved can see where you are, what your aims are and what the plan actually is, …rather than having to, to discuss the plan for 10 minutes and tell the new person, you know… if there's a form then everybody can just see, sort of what we're doing' (senior ICU doctor)

From many study participants there was a sense that integrated care pathways provide absolute clarity about processes of care. Much of the language used was of process and protocol, rather than uncertainty or grey areas.

'so it's clear on every patient this is what we're going to do, this is the process' (junior nurse)

Influence of health care provider experience

Several participants thought integrated care pathways for dying people were particularly beneficial for the more junior or inexperienced healthcare professional. Again, this was particularly related to processes of care: care pathways provided clarity and structure to the care delivered.

'…but I think it provides clear guidelines, in my experience, for junior staff to follow and it is very clear and easy to follow and I think it provides a nice framework.' (junior doctor)

However, a minority of interviewees expressed a different view: that integrated care pathways may be particularly poorly used by inexperienced staff. For example a consultant surgeon spoke about care pathways being used too rigidly by inexperienced colleagues:

'I think pathways ... give some kind of guideline which is helpful for people but often it is particularly young colleagues, it is something which makes them more inflexible... in the way that the most important thing if you work with pathways is to identify patients who don't fit in to the pathways because otherwise you make wrong decisions based on your pathways.' (senior surgeon)

The potential harms of integrated care pathways for the dying

Patient outcomes

In this study it was uncommon for staff members to talk about the impact of integrated care pathways on patient outcomes, and no participant spoke about integrated care pathways as improving the quality of patients' deaths. Where outcomes were discussed, these related to the potential for harm. The words 'dangerous' and 'danger' were used. Integrated care pathways were not thought to be intrinsically bad, but were susceptible to poor use.

The distinction between processes of care and patient outcomes was highlighted clearly by one participant:

'but it is documentation so it doesn't do the care for you, … and there's still an awful lot of thought and…work that you know needs to go into giving that care, … so it's not a tick box exercise, … and I think there's just a danger of that' (senior nurse)

Tick-box care

Several study participants expressed concern that end of life care needs to be individualised, and that integrated care pathways inhibit the necessary flexibility required to provide good care to the dying. One participant spoke about integrated care pathways promoting tick-box care and inhibiting thoughtfulness:

'Whatever care pathway there is, I'm always worried about people switching off their brains. Tick-boxing. Putting down on paper what they have to to fill in the paperwork.' (senior ICU doctor)

Another participant with extensive experience in palliative care spoke about the tension between providing holistic end of life care and following a pathway, and suggested that integrated care pathways may absolve healthcare professionals from clinical decision making:

'I think it's dangerous at the moment at times because that clinical decision-making doesn't happen, it isn't documented and in some instances the pathway, and that's not the intention of the pathway and the people who developed the pathway, but the presence of the pathway, the options of the pathway actually seems to absolve people from that.' (senior physician)

The symbolic value of integrated care pathways

A signal

Several participants described integrated care pathways for end of life care in a way that suggested a symbolic value. Pathways were considered to be a useful signal, even before the paperwork was filled in, to herald the change in focus of care from active to palliative treatment. For example, the presence of the paperwork at the bedside was described as a non-verbal form of communication that the focus of care had changed.

'When it does become a focus issue we very quickly get the paperwork out of the stationery cupboard and put it there [by the bed].' (senior nurse)

A change in focus

The availability of integrated care pathways for end of life care was felt to have a value in legitimising death as an outcome in hospital, providing an acceptable alternative to aggressive medical care. One ICU consultant spoke about integrated care pathways providing a positive focus to the change in patient care by highlighting the care which will be provided, rather than aspects of care that are thought no longer appropriate.

There was a sense, however, that the use of integrated care pathways may promote a binary attitude towards dying: integrated care pathways are either used or not used, therefore patients are either dying or not dying. This perceived clarity regarding the change in focus of care may give some clinicians permission to distance themselves from the patient's care entirely. One senior physician talked about 'switching off' when the LCP is used:

'I always joke about departments where, yes, the Liverpool Care Pathway is used in the department, do you know exactly what happens, by that stage you've switched off and you've handed the patient over, I think that's the honest truth.' (senior physician)

Infrastructure

Education and training

Education and training in palliative care was commented only occasionally. A few study participants volunteered that they had received palliative care training, and for those who had, this had often focused more on how to use the LCP paperwork than generic palliative care skills. For one participant, the LCP itself appeared to act as an educational tool:

'things like the Liverpool Care Pathway and things like that, I think they are a distillation of what I personally have been taught piecemeal over 10, 11 years now since graduation, and even before.' (senior ICU doctor)

Evidence

Only one study participant spoke about the evidence base for the LCP. This participant expressed concern about the lack of strong evidence for the benefits of LCP, and the lack of awareness among other medical colleagues about the paucity of evidence.

'…there is no evidence. It's not a validated tool' (senior physician)

Discussion

This study demonstrates that in the years preceding the Neuberger review, health care professionals were conscious of both benefits and harms of integrated care pathways for end of life care. The benefits related to streamlined processes of care, and were experienced by the health care professionals themselves. Potential harms related to applying the pathway inflexibly or without thinking, leading to poor clinical decision-making, and were reminiscent of criticisms subsequently published by the media and the Neuberger review.

It is notable that no participant in this study cited benefits regarding improved outcomes for patients. This does not mean that integrated care pathways do not have the potential to improve the quality of patients' end of life care, but it does suggest that health care professionals using them may lose sight of the ultimate goal of care: a good death for the patient and improved outcomes in bereavement for their carers. The LCP audits, which measured success of implementation based on process measures not patient-centred outcomes, may have reinforced this.[16]

The LCP was not intended as a protocol, but as a guide.[17] We found that it was often interpreted as a protocol, and moreover for many staff members, particularly those with least experience, this aspect was most valued. This may be because for many staff training and education in palliative care had been insufficient, for example focussed on documentation or provided 'piecemeal' over years. Integrated care pathways are not a substitute for skills, knowledge or expertise, but there may be a tendency for professionals, particularly those most junior, to interpret them as such. The importance of specialist palliative care team support and specialist training when implementing integrated care pathways for end of life care was highlighted in the first randomised trial of the LCP, published six months after the Neuberger review.[18] A qualitative study from the same group recently confirmed the importance of training in palliative care.[19]

One of the main criticisms made by the Neuberger review was the lack of prospective testing of the LCP. It is interesting that only one health care professional in this study cited the importance of knowing the evidence base for such a pathway. Professionals may consider research evidence less important or relevant when people are dying, and this may be compounded by the historical paucity of research funding for palliative care.[20] Patchy education and training in palliative care may have created a vacuum which allowed a tool for which there was no strong evidence to become accepted and valued. It is possible that the strong symbolic value of the LCP may, in turn, have made it easier for professionals to overlook the shortcomings in evidence.

The strengths of this study are that a large number of people were interviewed, from different grades within several medical, surgical and allied specialties. By using data collected in 2009, we are able to understand the views of health care professionals in the period before the media controversy and Neuberger review.

This study has limitations. The original study focussed on clinical uncertainty and dying in the ICU, and there are therefore a disproportionately large number of staff members from the ICU which may not be representative of the wider clinical setting. Attitudes towards integrated care pathways for end of life care was just one part of the original study and the interview schedule.

This study has important implications for the future development of interventions to improve end of life care. First, it demonstrates the importance of collecting qualitative data during development of complex interventions.[21] All interventions have benefits and harms, some of which may be obvious, others less so, especially when the intervention is complex.[22] Collecting such data during the early implementation of the LCP would have enabled it to be refined and improved.

Second, the study emphasises the importance of investment in education and training in palliative care. The enthusiasm for what was perceived to be a protocol for end of life care indicates a need for improved understanding of how to care for the dying. Without these generic skills, it is unlikely that staff members would be able to use any such tools well, or to recognise when they are being used poorly. In the case of the LCP, the introduction of financial targets may have exacerbated this.

Third, the study identifies the importance of grounding the development of any future tools to improve care of the dying around patient outcomes, not just processes. Measuring processes of care is often more straightforward than measuring outcomes. However, reliance on process measures not only meant that it was impossible to demonstrate whether the LCP improved quality of care for patients and families,[7] it may also have contributed to the staff who used it losing sight of the overall goals of care. Re-orientating health care professionals from processes to patient-centred outcomes is necessary to improve end of life care.

Competing interests

We declare that we have no competing interests.

Authors’ contributions

IJH, WP, JK, PH, SL, WB and MM planned the original study, wrote the protocol, won funding, and oversaw the original study. KES, KB, JK and IJH designed, planned and carried out analyses for this paper. IJH, WP, JK, PH, SL, WB, RB, OD, JN and MM formed the Project Advisory Group. KES drafted this manuscript and revised it in response to critical revisions from all authors. IJH and KES are the co-guarantors of the study. All authors read and approved the final manuscript.

Funding

This paper presents independent research funded by the National Institute for Health Research (NIHR) under its Research for Patient Benefit (RfPB) Programme (Grant Reference Number PB-PG-0107-12109). The views expressed are those of the authors, and are not necessarily those of the National Health Service, the National Institute for Health Research, the NIHR, or the Department of Health.

Acknowledgements

We are grateful to Dr Cathy Shipman (CS) who contributed greatly to the original study.

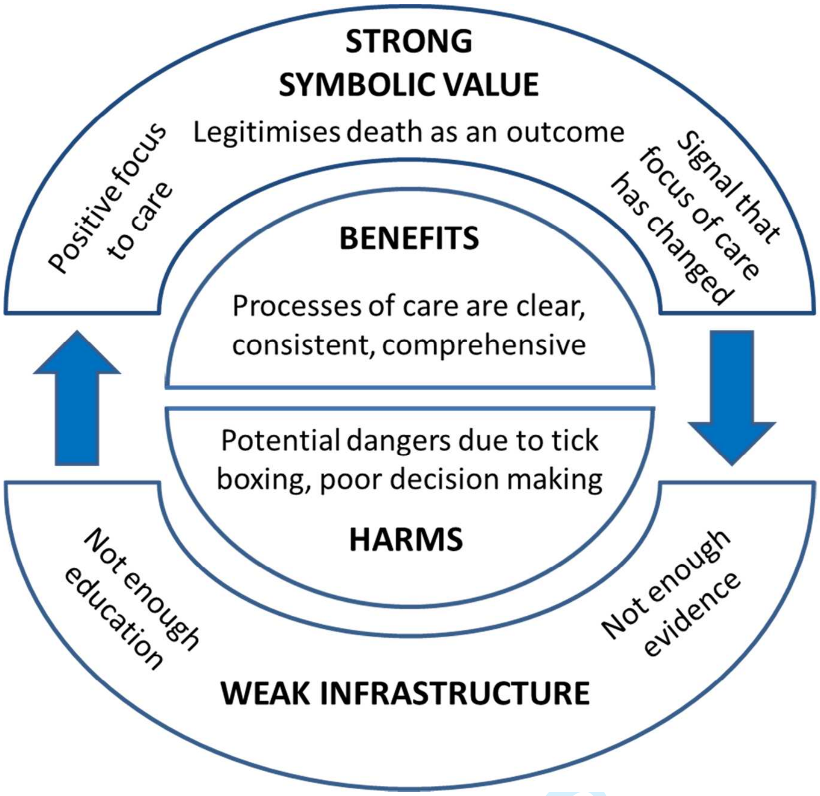

Figure 1: Model of health care professionals' perceptions of the benefits and harms of integrated care pathways for end of life care

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COREQ checklist,[1] including manuscript page number

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Item	Guide question	Page
Domain 1: Research team and reflexivity Personal Characteristics	1. Interviewer/facilitator Which author/s conducted the interview or focus group?	7
	2. Credentials What were the researcher's credentials? E.g. PhD, MD	7
	3. Occupation What was their occupation at the time of the study?	7
	4. Gender Was the researcher male or female?	1
	5. Experience and training What experience or training did the researcher have?	7
Relationship with participants	6. Relationship established Was a relationship established prior to study commencement?	7
	7. Participant knowledge of the interviewer What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	7
	8. Interviewer characteristics What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	7
Domain 2: Study design Theoretical framework	9. Methodological orientation and Theory What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	8
Participant selection	10. Sampling How were participants selected? e.g. purposive, convenience, consecutive, snowball	7
	11. Method of approach How were participants approached? e.g. face-to-face, telephone, mail, email	7
	12. Sample size How many participants were in the study?	7
	13. Non-participation How many people refused to participate or dropped out? Reasons?	
Setting	14. Setting of data collection Where was the data collected? e.g. home, clinic, workplace	7
	15. Presence of non-participants Was anyone else present besides the participants and researchers?	7
	16. Description of sample What are the important characteristics of the sample? e.g. demographic data, date	7
Data collection	17. Interview guide Were questions, prompts, guides provided by the authors? Was it pilot tested?	7
	18. Repeat interviews Were repeat interviews carried out? If yes, how many?	7
	19. Audio/visual recording Did the research use audio or	7-8

	visual recording to collect the data?	
	20. Field notes Were field notes made during and/or after the interview or focus group?	7
	21. Duration What was the duration of the interviews or focus group?	7
	22. Data saturation Was data saturation discussed?	8
	23. Transcripts returned Were transcripts returned to participants for comment and/or correction?	8
Domain 3: analysis and findings Data analysis	24. Number of data coders How many data coders coded the data?	8
	25. Description of the coding tree Did authors provide a description of the coding tree?	8
	26. Derivation of themes Were themes identified in advance or derived from the data?	8
	27. Software What software, if applicable, was used to manage the data?	8
	28. Participant checking Did participants provide feedback on the findings?	8
Reporting	29. Quotations presented Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number	8-13
	30. Data and findings consistent Was there consistency between the data presented and the findings?	8-13
	31. Clarity of major themes Were major themes clearly presented in the findings?	8-13
	32. Clarity of minor themes Is there a description of diverse cases or discussion of minor themes?	8-13

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Journal:	*BMJ Open*
Manuscript ID:	bmjopen-2015-008242.R1
Article Type:	Research
Date Submitted by the Author:	18-Jun-2015
Complete List of Authors:	Sleeman, Katherine; King’s College London, Cicely Saunders Institute, Department of Palliative Care, Policy and Rehabilitation Koffman, Jonathan ; King’s College London, Cicely Saunders Institute, Department of Palliative Care, Policy and Rehabilitation Bristowe, Katherine; King’s College London, Cicely Saunders Institute, Department of Palliative Care, Policy and Rehabilitation Rumble, Caroline; King’s College London, Cicely Saunders Institute, Department of Palliative Care, Policy and Rehabilitation Burman, Rachel; King’s College London, Cicely Saunders Institute, Department of Palliative Care, Policy and Rehabilitation Leonard, Sara; King's College HospitalNHS Foundation Trust, Intensive Care Unit Noble, Jo; King's College HospitalNHS Foundation Trust, Intensive Care Unit Dampier, Odette; King's College HospitalNHS Foundation Trust, Intensive Care Unit Bernal, William; King's College HospitalNHS Foundation Trust, Intensive Care Unit Morgan, Myfanwy; King's College London, Primary Care & Public Health Sciences Hopkins, Philip; King's College HospitalNHS Foundation Trust, Intensive Care Unit Prentice, Wendy; King’s College London, Cicely Saunders Institute, Department of Palliative Care, Policy and Rehabilitation Higginson, Irene; King’s College London, Cicely Saunders Institute, Department of Palliative Care, Policy and Rehabilitation
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Keywords:	Adult palliative care < PALLIATIVE CARE, GENERAL MEDICINE (see Internal Medicine), Health policy < HEALTH SERVICES ADMINISTRATION & MANAGEMENT

‘It doesn’t do the care for you’: a qualitative study of health care professionals’ perceptions of the benefits and harms of integrated care pathways for end of life care

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Objectives: To understand health care professionals' perceptions of the benefits and potential harms of integrated care pathways for end of life care, to inform the development of future interventions that aim to improve care of the dying.

Design: Qualitative interview study with maximum variation sampling and thematic analysis.

Participants: 25 health care professionals including doctors, nurses and allied health professionals, interviewed in 2009.

Setting: A 950 bed South London teaching hospital.

Results: Four main themes emerged, each including two sub-themes. Participants were divided between those who described mainly (i) benefits of integrated care pathways, and those who talked about (ii) potential harms. Benefits focused on processes of care, e.g. clearer, consistent, and comprehensive actions. The recipients of these benefits were staff members themselves, particularly juniors. For others, this perceived clarity was interpreted as of potential harm to patients, where over-reliance on paperwork lead to prescriptive, less thoughtful care, and an absolution from decision-making. Independent of their effects on patient care, integrated care pathways for dying had a (iii) symbolic value: they legitimised death as a potential outcome and were used as a signal that the focus of care had changed. However, (iv) weak infrastructure including scanty education and training in end of life care and a poor evidence base, appeared to undermine the foundations on which the Liverpool Care Pathway was built.

Conclusions: The potential harms of integrated care pathways for dying identified in this study were reminiscent of criticisms subsequently published by the Neuberger review. These data highlight: (i) the importance of collecting, reporting, and using qualitative data when developing and evaluating complex interventions; (ii) that comprehensive education and training in palliative care is critical for

the success of any new intervention; (iii) the need for future interventions to be grounded in patient-centred outcomes, not just processes of care.

Strengths and limitations

Qualitative research has an important role in shaping complex interventions to ensure that they are appropriate, acceptable and feasible in the chosen setting, but such approaches can be undervalued. This in depth qualitative study examines health care professionals' perceptions of the benefits and harms of integrated care pathways for end of life care in order to inform the development of interventions to improve care for the dying.

We interviewed health care professionals from different grades and within medical, surgical and allied specialties, and have developed detailed insights into the factors associated with successful implementation of integrated care pathways for end of life care.

By using data collected in 2009, we are able to understand the views of health care professionals in the period before the media controversy surrounding the use of the Liverpool care Pathway and Neuberger review.

We interviewed a disproportionately large number of staff members from the Intensive Care Unit, and participants were from a single tertiary referral centre, which may not be representative of the wider clinical setting.

Introduction

Qualitative research, including exploration of patient, carer and health care professional perspectives, has an important role in shaping complex interventions to ensure that they are appropriate, acceptable and feasible. In the context of controlled trials, qualitative research can be used to understand the complexity of interventions and the context in which they are tested.[1] However, qualitative research can be poorly integrated with other methods of evaluation, and may be undervalued.[2]

The Liverpool Care Pathway for the Dying Patient (LCP), an integrated care pathway for end of life care, was developed in England in the late 1990s.[3] It aimed to distil the most important elements of good end of life care from the hospice setting, and transform them into a framework to guide and improve care in hospital, care home and community settings. The LCP provides prompts and guidance within a structured single record, to promote the delivery of good care to people thought to be dying within hours or days, and was developed for use by doctors, nurses and allied health professionals inexpert in palliative care. It rapidly became suggested as a model of good practice by the UK Department of Health and it formed an integral part of the National End of Life Care Programme.[4] The LCP (or modified versions of it) was subsequently introduced in the United States, Australia, China and Europe.[5]

The aim of any integrated care pathway is to improve patient outcomes by promoting consistency and streamlining processes of care.[6] Although there was evidence that the LCP improved processes of care, for example anticipatory prescribing of drugs for symptom control, prospective evidence of its benefits to patient outcomes, for example improvement in symptoms, was lacking.[7-9] In 2013, following intense media scrutiny in the British press of its potential harms, an Independent Review led by Baroness Neuberger identified numerous examples of poor care associated with the LCP, including poor communication, patchy senior decision-making, and accounts of patients who appeared to have been over-sedated or denied food and drink. The panel concluded that in the absence of reliable evidence of the pathway's benefits,[8,9] its use could no longer be justified.[10]

The extent to which health care professionals were aware of and in agreement with the potential harms exposed by the media and Neuberger review is unclear. Health care professionals' views around the LCP were studied prior to the Neuberger review, but these studies cited mainly positive attitudes towards the impact of the LCP on the processes of care, for example improvement in communication, continuity, documentation, and as an educational tool.[11-14] None cited harms similar to those reported in the Neuberger review. However, these studies were limited in terms of the population included.

Understanding the a priori reservations of health care professionals regarding potential harms of integrated care pathways for end of life care would help inform the implementation of the LCP outside the UK where it is still being used,[15] and the development of any future interventions to improve care of the dying. We analysed data collected in 2009 as part of a mixed methods study to develop and implement a tool to improve palliative and end of life care in Intensive Care Units (ICUs),[16] a setting where end of life decision making is complex and multifactorial. The original study collected data on the perceptions of health care professionals towards integrated care pathways for end of life care, including the LCP. The data were collected long before the issues were raised strongly in the British press and four years before the Neuberger review reported. One of the aims of the original study was to explore the views expressed by professionals about the potential benefits and harms of care pathways at the end of life. The findings are presented here, and compared to those issues subsequently identified by the Neuberger review.

Methods

Design

This was a qualitative analysis of interviews with health care professionals. The data were collected as part of a study which followed guidance for the development and evaluation of complex interventions from the Medical Research Council (the UK Government agency responsible for coordinating and funding medical research),[17] and the Methods of Researching End-of-Life Care (MORECare) statement of good practice[18], to develop and assess a tool to improve palliative and end of life care in ICU. The original study and the results are published elsewhere.[16] The study was granted ethical approval by the South East London REC (08/H0805/65 and 08/H808/103) and received full hospital Research and Development approval.

Setting

The setting was two adult ICUs in a 950 bed South London teaching hospital, serving an area characterised by social deprivation and culturally and ethnically heterogeneous populations. At the time of the study the LCP had been implemented across much of the hospital, but was not used routinely in the Intensive Care Setting.

Participants

Maximum variation sampling was used to select potential staff participants to gain perspectives from a broad range of health care professionals, taking into account age, gender, profession and experience, and included both ICU and other hospital staff. Staff were identified through discussion with key staff members, and approached by letter or email. Written informed consent was gained from each participant prior to interview. 25 participants were interviewed: 13 nurses (junior to senior), six ICU doctors (junior to senior), one transplant coordinator, two social workers, two senior physicians and one senior surgeon. Three participants had extensive palliative care experience. All participants had some familiarity with integrated care pathways for end of life care including the LCP, though experience varied by clinical setting and grade. Interviews were carried out in 2009.

Data collection

An interview time convenient to the healthcare professional was arranged (outside of clinical duties). Interviews were conducted in a confidential setting away from the clinical workplace unless the participant preferred not to. Interviews lasted 30-60 minutes and were conducted face to face with one of two trained interviewers (CS (MSc), a senior research fellow and an experienced qualitative researcher, with an interest in non-specialist provision of palliative care; CR (MBChB MPH), a clinical research associate trained in qualitative methods). No relationship had been established prior to study commencement, and there were no non-participants present. Topic guides were developed from a literature review, initial observations and discussions with service users, and explored perceptions, recommendations and views on integrated care pathways for palliative and end of life care (including the LCP), processes of decision making, and experiences of palliative and end of life care. Although the study was based in the ICU, questions were concerned with the use of integrated care pathways more generally. Questions were open-ended, and were piloted and revised. No repeat interviews were carried out. All interviews were digitally recorded and transcribed verbatim. The data were anonymised and code numbers allocated to each case. Themes were fed back and data were discussed with the project advisory group and with participants.

Analysis

We used thematic analysis to inductively identify patterns and themes within the data. This approach utilises five related steps of: familiarisation, coding, theme development, defining themes and reporting.[19] All interview data were reviewed during the process of familiarisation, and all sections of the interviews relating to the experience of utilising integrated care pathways were extracted. Emergent themes were identified from the data, defined and reported through an iterative process of theme development.

The primary data coder was KES. Specialist software was not used. To address issues of analytical rigor and trustworthiness, a subset of transcripts were double-coded by KB. A re-iterant process of discussing areas of agreement and disagreement took place between KES and KB to achieve consensus. Alternative interpretations were incorporated in the analysis. The analysis was further tested during discussions with colleagues, and meetings of the project advisory steering group. We also paid attention to non-confirmatory cases where emerging themes contradicted more common ideas. Quotations were chosen to illustrate the themes, and to include a range of study participants.

Results

Four themes were identified from the interview transcripts, each including two sub-themes. Participants were divided between those who cited mainly benefits of integrated care pathways, and those who talked about potential harms. In addition, integrated care pathways for dying appeared to have a symbolic value, acting as a signal that the focus of care had changed. Underlying this were comments relating to the context and infrastructure within which care was provided (Figure 1).

The benefits of integrated care pathways for the dying

Processes of care

Many participants cited benefits of integrated care pathways for dying with respect to processes of care. The LCP provides a structured single record with prompts to guide care, and nursing staff in particular appeared to value the structure that integrated care pathways provide. There was frequent mention of improved clarity about the care which was to be provided.

'I think perhaps it does mean that everybody has a clear picture as to what we are doing and not doing.' (senior nurse)

Integrated care pathways were felt to make care of the dying more consistent and comprehensive, and were felt to be particularly valuable in situations where continuity was compromised, for example out of hours or when turnover of staff (medical or nursing) was high.

'The biggest challenge I find as a nurse is not really knowing where you stand sometimes with treatment with, you know, perhaps the weekend…that's why I think the pathway is a good thing because it gives people guidance and gives us nurses something to follow.' (senior nurse)

An extreme view was that integrated care pathways for end of life care could provide a substitute for face-to-face handover between health care professionals changing shifts.

'So having a form …can make sure that everybody involved can see where you are, what your aims are and what the plan actually is, …rather than having to, to discuss the plan for 10 minutes and tell the new person, you know… if there's a form then everybody can just see, sort of what we're doing' (senior ICU doctor)

From many study participants there was a sense that integrated care pathways provide absolute clarity about processes of care. Much of the language used was of process and protocol, rather than uncertainty or grey areas.

'so it's clear on every patient this is what we're going to do, this is the process' (junior nurse)

Influence of health care provider experience

Several participants thought integrated care pathways for dying people were particularly beneficial for the more junior or inexperienced healthcare professionals. Again, this was particularly related to processes of care: care pathways provided clarity and structure to the care delivered.

'…but I think it provides clear guidelines, in my experience, for junior staff to follow and it is very clear and easy to follow and I think it provides a nice framework.' (junior doctor)

However, a minority of interviewees expressed a different view: that integrated care pathways may be particularly poorly used by inexperienced staff. For example a consultant surgeon spoke about care pathways being used too rigidly by inexperienced colleagues.

'I think pathways ... give some kind of guideline which is helpful for people but often it is particularly young colleagues, it is something which makes them more inflexible... in the way that the most important thing if you work with pathways is to identify patients who don't fit in to the pathways because otherwise you make wrong decisions based on your pathways.' (senior surgeon)

The potential harms of integrated care pathways for the dying

Patient outcomes

In this study it was uncommon for staff members to talk about the impact of integrated care pathways on patient outcomes, and no participant spoke about integrated care pathways as improving the quality of patients' deaths. Where outcomes were discussed, these related to the potential for harm. The words 'dangerous' and 'danger' were used. Integrated care pathways were not thought to be intrinsically bad, but were susceptible to poor use.

The distinction between processes of care and patient outcomes was highlighted clearly by one participant.

'but it is documentation so it doesn't do the care for you, … and there's still an awful lot of thought and…work that you know needs to go into giving that care, … so it's not a tick box exercise, … and I think there's just a danger of that' (senior nurse)

Tick-box care

Several study participants expressed concern that end of life care needs to be individualised, and that the structure of integrated care pathways, which in the case of the LCP included 4 hourly and 12 hourly prompts, can inhibit the necessary flexibility required to provide good care to the dying. One participant spoke about integrated care pathways promoting tick-box care and inhibiting thoughtfulness.

'Whatever care pathway there is, I'm always worried about people switching off their brains. Tick-boxing. Putting down on paper what they have to to fill in the paperwork.' (senior ICU doctor)

Another participant with extensive experience in palliative care spoke about the tension between providing holistic end of life care and following a pathway, and suggested that integrated care pathways may absolve healthcare professionals from clinical decision making.

'I think it's dangerous at the moment at times because that clinical decision-making doesn't happen, it isn't documented and in some instances the pathway, and that's not the intention of the pathway and the people who developed the pathway, but the presence of the pathway, the options of the pathway actually seems to absolve people from that.' (senior physician)

The symbolic value of integrated care pathways

A signal

Several participants described integrated care pathways for end of life care in a way that suggested a symbolic value. Pathways were considered to be a useful signal, even before the paperwork was filled in, to herald the change in focus of care from active to palliative treatment. For example, the presence of the paperwork at the bedside was described as a non-verbal form of communication that the focus of care had changed.

'When it does become a focus issue we very quickly get the paperwork out of the stationery cupboard and put it there [by the bed].' (senior nurse)

A change in focus

The availability of integrated care pathways for end of life care was felt to have a value in legitimising death as an outcome in hospital, providing an acceptable alternative to aggressive medical care. One ICU consultant spoke about integrated care pathways providing a positive focus to the change in patient care by highlighting the care which will be provided, rather than aspects of care that are thought no longer appropriate.

There was a sense, however, that the use of integrated care pathways may promote a binary attitude towards dying: integrated care pathways are either used or not used, therefore patients are either dying or not dying. This perceived clarity regarding the change in focus of care may give some clinicians permission to distance themselves from the patient's care entirely. One senior physician talked about 'switching off' when the LCP is used.

'I always joke about departments where, yes, the Liverpool Care Pathway is used in the department, do you know exactly what happens, by that stage you've switched off and you've handed the patient over, I think that's the honest truth.' (senior physician)

Infrastructure

Education and training

Education and training in palliative care were commented only occasionally. A few study participants volunteered that they had received palliative care training, and for those who had, this had often focused more on how to use the LCP paperwork than generic palliative care skills. For one participant, the LCP itself appeared to act as an educational tool.

'things like the Liverpool Care Pathway and things like that, I think they are a distillation of what I personally have been taught piecemeal over 10, 11 years now since graduation, and even before.' (senior ICU doctor)

Evidence

Only one study participant spoke about the evidence base for the LCP. This participant expressed concern about the lack of strong evidence of the benefits of the LCP, and the lack of awareness among other medical colleagues about the paucity of evidence.

'…there is no evidence. It's not a validated tool' (senior physician)

Discussion

This study demonstrates that in the years preceding the Neuberger review, health care professionals were conscious of both benefits and harms of integrated care pathways for end of life care. The benefits related to streamlined processes of care, and were experienced by the health care professionals themselves. Potential harms related to applying the pathway inflexibly or without thinking, leading to poor clinical decision-making, and were reminiscent of criticisms subsequently published by the media and the Neuberger review.

It is notable that no participant in this study cited benefits regarding improved outcomes for patients. This does not mean that integrated care pathways do not have the potential to improve the quality of patients' end of life care, but it does suggest that health care professionals using them may lose sight of the ultimate goal of care: a good death for the patient and improved outcomes in bereavement for their carers. The LCP audits, which measured success of implementation based on process measures not patient-centred outcomes, may have reinforced this.[20]

The LCP was not intended as a protocol, but as a guide.[21] We found that it was often interpreted as a protocol, and moreover for many staff members, particularly the more junior clinicians, this aspect was particularly valued. This may be because for many staff training and education in palliative care had been fragmented and unsystematic, for example focussed on documentation or provided ‘piecemeal’ over years. It was the more senior clinicians who identified potential harms of integrated care pathways in this study, including relying on them too heavily as protocols. This may reflect their more extensive clinical experience, and overall responsibility for patient care. Integrated care pathways are not a substitute for skills, knowledge or expertise, but there may be a tendency for professionals, particularly those most junior, to interpret them as such. The importance of specialist palliative care team support and specialist training when implementing integrated care pathways for end of life care was highlighted in the first randomised trial of the LCP, published six months after the Neuberger review.[22][23]

Although the LCP was intended simply as a guide to care, it fulfilled additional roles. An integrated care pathway for end of life care acted as a symbol to herald the change from curative to palliative treatment, to signal to others that the focus of care had changed, and to legitimise that change. Indeed, for some clinicians the perceived clarity of this switch in the focus of care appeared to allow them to distance themselves from the patients’ care entirely.

One of the main criticisms made by the Neuberger review was the lack of prospective testing of the LCP. It is interesting that only one health care professional in this study cited the importance of knowing the evidence base for such a pathway. Professionals may consider research evidence less important or relevant when people are dying, and this may be compounded by the historical paucity of research funding for palliative care.[24] Patchy education and training in palliative care may have created a vacuum that allowed a tool for which there was no strong evidence to become accepted and valued. The strong symbolic value of the LCP may, in turn, have made it easier for professionals to overlook the shortcomings in evidence.

The strengths of this study are that a large number of people were interviewed, from different grades within several medical, surgical and allied specialties. By using data collected in 2009, we are able to understand the views of health care professionals in the period before the media controversy and Neuberger review.

This study has limitations. The original study focussed on dying in the ICU, where rapid changes in health status and prognostic uncertainty are common. The disproportionately large number of staff members from the ICU in this study may therefore not be representative of the wider clinical setting. Attitudes towards integrated care pathways for end of life care was just one part of the original study and the interview schedule.

This study has important implications for the future development of interventions to improve end of life care. First, it demonstrates the importance of collecting, reporting, and using qualitative data during the development of complex interventions.[25] All interventions have benefits and harms, some of which may be obvious, others less so, especially when the intervention is complex.[26] Collecting such data, including patient, carer, and health care professional perspectives, during the early implementation of an integrated care pathway for end of life care would enable it to be refined and improved.

Second, the study emphasises the importance of investment in education and training in palliative care. The enthusiasm for what was perceived to be a protocol for end of life care indicates a need for improved understanding of how to care for the dying. Without these generic skills, it is unlikely that staff members would be able to use any such tools well, or to recognise when they are being used poorly.

Third, the study identifies the importance of grounding the development of any future tools to improve care of the dying around patient outcomes, not just processes. Measuring processes of care is often more straightforward than measuring outcomes. However, reliance on process measures not only meant that it was impossible to demonstrate whether the LCP improved quality of care for patients and families,[10] it may also have contributed to the staff who used it losing sight of the overall goals of care. Re-orientating health care professionals from processes to patient-centred outcomes is necessary to improve end of life care.

Competing interests

We declare that we have no competing interests.

Authors' contributions

IJH, WP, JK, PH, SL, WB and MM planned the original study, wrote the protocol, won funding, and oversaw the original study. KES, KB, JK and IJH designed, planned and carried out analyses for this paper. IJH, WP, JK, PH, SL, WB, RB, OD, JN and MM formed the Project Advisory Group. KES drafted this manuscript and revised it in response to critical revisions from all authors. IJH and KES are the co-guarantors of the study. All authors read and approved the final manuscript.

Funding

This paper presents independent research funded by the National Institute for Health Research (NIHR) under its Research for Patient Benefit (RfPB) Programme (Grant Reference Number PB-PG-0107-12109). The Collaboration for Leadership in Applied Health Research and Care (CLAHRC) South London is part of the National Institute for Health Research (NIHR), and is a partnership between King's Health Partners, St. George's, University London, and St George's Healthcare NHS Trust. This report is independent research funded by the National Institute for Health Research Collaboration for Leadership in Applied Health Research & Care Funding scheme. The views expressed are those of the authors, and are not necessarily those of the National Health Service, the National Institute for Health Research, the NIHR, or the Department of Health.

Acknowledgements

We are grateful to Dr Cathy Shipman (CS) who contributed greatly to the original study.

Figure legend

Figure 1: Model of health care professionals' perceptions of the benefits and harms of integrated care pathways for end of life care

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COREQ checklist,[1] including manuscript page number

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Item	Guide question	Page
Domain 1: Research team and reflexivity Personal Characteristics	1. Interviewer/facilitator Which author/s conducted the interview or focus group?	7
	2. Credentials What were the researcher's credentials? E.g. PhD, MD	7
	3. Occupation What was their occupation at the time of the study?	7
	4. Gender Was the researcher male or female?	1
	5. Experience and training What experience or training did the researcher have?	7
Relationship with participants	6. Relationship established Was a relationship established prior to study commencement?	7
	7. Participant knowledge of the interviewer What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	7
	8. Interviewer characteristics What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	7
Domain 2: Study design Theoretical framework	9. Methodological orientation and Theory What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	8
Participant selection	10. Sampling How were participants selected? e.g. purposive, convenience, consecutive, snowball	7
	11. Method of approach How were participants approached? e.g. face-to-face, telephone, mail, email	7
	12. Sample size How many participants were in the study?	7
	13. Non-participation How many people refused to participate or dropped out? Reasons?	
Setting	14. Setting of data collection Where was the data collected? e.g. home, clinic, workplace	7
	15. Presence of non-participants Was anyone else present besides the participants and researchers?	7
	16. Description of sample What are the important characteristics of the sample? e.g. demographic data, date	7
Data collection	17. Interview guide Were questions, prompts, guides provided by the authors? Was it pilot tested?	7
	18. Repeat interviews Were repeat interviews carried out? If yes, how many?	7
	19. Audio/visual recording Did the research use audio or	7-8

	visual recording to collect the data?	
	20. Field notes Were field notes made during and/or after the interview or focus group?	7
	21. Duration What was the duration of the interviews or focus group?	7
	22. Data saturation Was data saturation discussed?	8
	23. Transcripts returned Were transcripts returned to participants for comment and/or correction?	8
Domain 3: analysis and findings Data analysis	24. Number of data coders How many data coders coded the data?	8
	25. Description of the coding tree Did authors provide a description of the coding tree?	8
	26. Derivation of themes Were themes identified in advance or derived from the data?	8
	27. Software What software, if applicable, was used to manage the data?	8
	28. Participant checking Did participants provide feedback on the findings?	8
Reporting	29. Quotations presented Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number	8-13
	30. Data and findings consistent Was there consistency between the data presented and the findings?	8-13
	31. Clarity of major themes Were major themes clearly presented in the findings?	8-13
	32. Clarity of minor themes Is there a description of diverse cases or discussion of minor themes?	8-13

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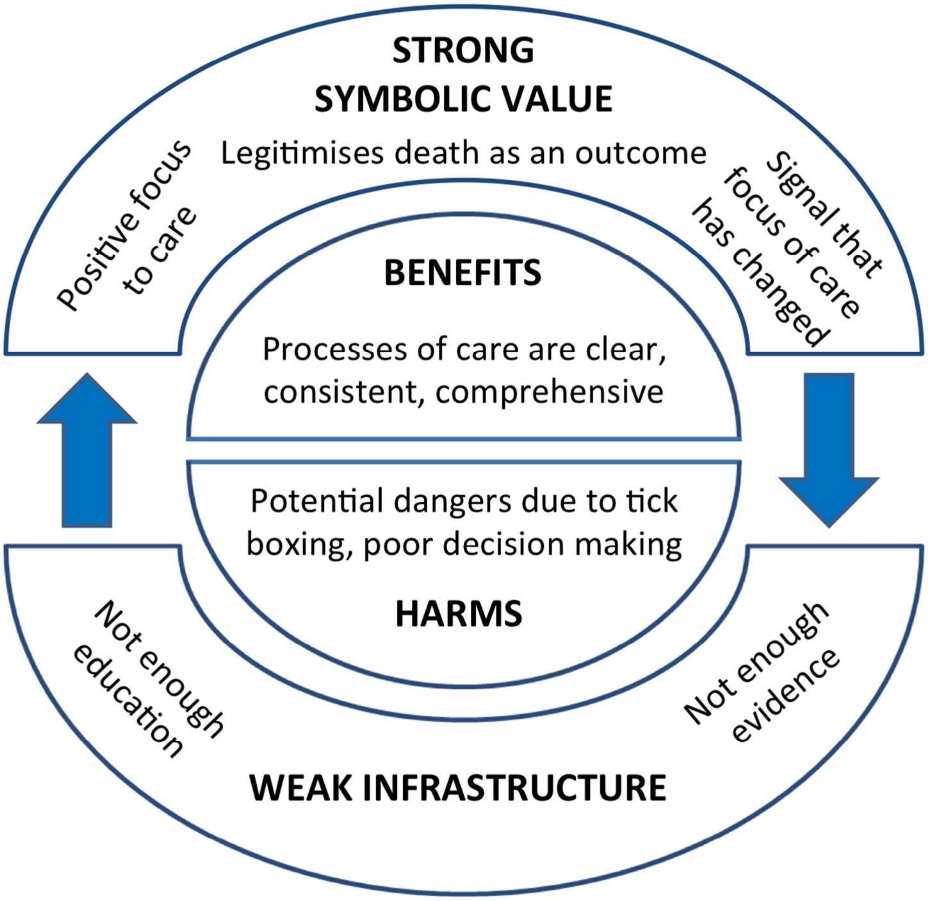

Figure 1: Model of health care professionals' perceptions of the benefits and harms of integrated care pathways for end of life care
498x483mm (300 x 300 DPI)

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Journal:	*BMJ Open*
Manuscript ID:	bmjopen-2015-008242.R2
Article Type:	Research
Date Submitted by the Author:	06-Jul-2015
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Primary Subject Heading:	Palliative care
Secondary Subject Heading:	Palliative care, Health policy, Qualitative research
Keywords:	Adult palliative care < PALLIATIVE CARE, GENERAL MEDICINE (see Internal Medicine), Health policy < HEALTH SERVICES ADMINISTRATION & MANAGEMENT

‘It doesn’t do the care for you’: a qualitative study of health care professionals’ perceptions of the benefits and harms of integrated care pathways for end of life care

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Objectives: To understand health care professionals' perceptions of the benefits and potential harms of integrated care pathways for end of life care, to inform the development of future interventions that aim to improve care of the dying.

Design: Qualitative interview study with maximum variation sampling and thematic analysis.

Participants: 25 health care professionals including doctors, nurses and allied health professionals, interviewed in 2009.

Setting: A 950 bed South London teaching hospital.

Results: Four main themes emerged, each including two sub-themes. Participants were divided between those who described mainly (i) benefits of integrated care pathways, and those who talked about (ii) potential harms. Benefits focused on processes of care, e.g. clearer, consistent, and comprehensive actions. The recipients of these benefits were staff members themselves, particularly juniors. For others, this perceived clarity was interpreted as of potential harm to patients, where over-reliance on paperwork lead to prescriptive, less thoughtful care, and an absolution from decision-making. Independent of their effects on patient care, integrated care pathways for dying had a (iii) symbolic value: they legitimised death as a potential outcome and were used as a signal that the focus of care had changed. However, (iv) weak infrastructure including scanty education and training in end of life care and a poor evidence base, appeared to undermine the foundations on which the Liverpool Care Pathway was built.

Conclusions: The potential harms of integrated care pathways for dying identified in this study were reminiscent of criticisms subsequently published by the Neuberger review. These data highlight: (i) the importance of collecting, reporting, and using qualitative data when developing and evaluating complex interventions; (ii) that comprehensive education and training in palliative care is critical for

the success of any new intervention; (iii) the need for future interventions to be grounded in patient-centred outcomes, not just processes of care.

Strengths and limitations

Qualitative research has an important role in shaping complex interventions to ensure that they are appropriate, acceptable and feasible in the chosen setting, but such approaches can be undervalued. This in depth qualitative study examines health care professionals' perceptions of the benefits and harms of integrated care pathways for end of life care in order to inform the development of interventions to improve care for the dying.

We interviewed health care professionals from different grades and within medical, surgical and allied specialties, and have developed detailed insights into the factors associated with successful implementation of integrated care pathways for end of life care.

By using data collected in 2009, we are able to understand the views of health care professionals in the period before the media controversy surrounding the use of the Liverpool care Pathway and Neuberger review.

We interviewed a disproportionately large number of staff members from the Intensive Care Unit, and participants were from a single tertiary referral centre, which may not be representative of the wider clinical setting.

Introduction

Qualitative research, including exploration of patient, carer and health care professional perspectives, has an important role in shaping complex interventions to ensure that they are appropriate, acceptable and feasible. In the context of controlled trials, qualitative research can be used to understand the complexity of interventions and the context in which they are tested.[1] However, qualitative research can be poorly integrated with other methods of evaluation, and may be undervalued.[2]

The Liverpool Care Pathway for the Dying Patient (LCP), an integrated care pathway for end of life care, was developed in England in the late 1990s.[3] It aimed to distil the most important elements of good end of life care from the hospice setting, and transform them into a framework to guide and improve care in hospital, care home and community settings. The LCP provides prompts and guidance within a structured single record, to promote the delivery of good care to people thought to be dying within hours or days, and was developed for use by doctors, nurses and allied health professionals inexpert in palliative care. It rapidly became suggested as a model of good practice by the UK Department of Health and it formed an integral part of the National End of Life Care Programme.[4] The LCP (or modified versions of it) was subsequently introduced in the United States, Australia, China and Europe.[5]

The aim of any integrated care pathway is to improve patient outcomes by promoting consistency and streamlining processes of care.[6] Although there was evidence that the LCP improved processes of care, for example anticipatory prescribing of drugs for symptom control, prospective evidence of its benefits to patient outcomes, for example improvement in symptoms, was lacking.[7-9] In 2013, following intense media scrutiny in the British press of its potential harms, an Independent Review led by Baroness Neuberger identified numerous examples of poor care associated with the LCP, including poor communication, patchy senior decision-making, and accounts of patients who appeared to have been over-sedated or denied food and drink. The panel concluded that in the absence of reliable evidence of the pathway's benefits,[8,9] its use could no longer be justified.[10]

The extent to which health care professionals were aware of and in agreement with the potential harms exposed by the media and Neuberger review is unclear. Health care professionals' views around the LCP were studied prior to the Neuberger review, but these studies cited mainly positive attitudes towards the impact of the LCP on the processes of care, for example improvement in communication, continuity, documentation, and as an educational tool.[11-14] None cited harms similar to those reported in the Neuberger review. However, these studies were limited in terms of the population included.

Understanding the a priori reservations of health care professionals regarding potential harms of integrated care pathways for end of life care would help inform the implementation of the LCP outside the UK where it is still being used,[15] and the development of any future interventions to improve care of the dying. We analysed data collected in 2009 as part of a mixed methods study to develop and implement a tool to improve palliative and end of life care in Intensive Care Units (ICUs),[16] a setting where end of life decision making is complex and multifactorial. The original study collected data on the perceptions of health care professionals towards integrated care pathways for end of life care, including the LCP. The data were collected long before the issues were raised strongly in the British press and four years before the Neuberger review reported. One of the aims of the original study was to explore the views expressed by professionals about the potential benefits and harms of care pathways at the end of life. The findings are presented here, and compared to those issues subsequently identified by the Neuberger review.

Methods

Design

This was a qualitative analysis of interviews with health care professionals. The data were collected as part of a study which followed guidance for the development and evaluation of complex interventions from the Medical Research Council (the UK Government agency responsible for coordinating and funding medical research),[17] and the Methods of Researching End-of-Life Care (MORECare) statement of good practice[18], to develop and assess a tool to improve palliative and end of life care in ICU. The original study and the results are published elsewhere.[16] The study was granted ethical approval by the South East London REC (08/H0805/65 and 08/H808/103) and received full hospital Research and Development approval.

Setting

The setting was two adult ICUs in a 950 bed South London teaching hospital, serving an area characterised by social deprivation and culturally and ethnically heterogeneous populations. At the time of the study the LCP had been implemented across much of the hospital, but was not used routinely in the Intensive Care Setting.

Participants

Maximum variation sampling was used to select potential staff participants to gain perspectives from a broad range of health care professionals, taking into account age, gender, profession and experience, and included both ICU and other hospital staff. Staff were identified through discussion with key staff members, and approached by letter or email. Written informed consent was gained from each participant prior to interview. 25 participants were interviewed: 13 nurses (junior to senior), six ICU doctors (junior to senior), one transplant coordinator, two social workers, two senior physicians and one senior surgeon. Three participants had extensive palliative care experience. All participants had some familiarity with integrated care pathways for end of life care including the LCP, though experience varied by clinical setting and grade. Interviews were carried out in 2009.

Data collection

An interview time convenient to the healthcare professional was arranged (outside of clinical duties). Interviews were conducted in a confidential setting away from the clinical workplace unless the participant preferred not to. Interviews lasted 30-60 minutes and were conducted face to face with one of two trained interviewers (CS (MSc), a senior research fellow and an experienced qualitative researcher, with an interest in non-specialist provision of palliative care; CR (MBChB MPH), a clinical research associate trained in qualitative methods). No relationship had been established prior to study commencement, and there were no non-participants present. Topic guides were developed from a literature review, initial observations and discussions with service users, and explored perceptions, recommendations and views on integrated care pathways for palliative and end of life care (including the LCP), processes of decision making, and experiences of palliative and end of life care. Although the study was based in the ICU, questions were focused on the use of integrated care pathways more generally. Questions were open-ended, and were piloted and revised. No repeat interviews were carried out. All interviews were digitally recorded and transcribed verbatim. The data were anonymised and code numbers allocated to each case. Themes were fed back and data were discussed with the project advisory group and with participants.

Analysis

We used thematic analysis to inductively identify patterns and themes within the data. This approach utilises five related steps of: familiarisation, coding, theme development, defining themes and reporting.[19] All interview data were reviewed during the process of familiarisation, and all sections of the interviews relating to the experience of utilising integrated care pathways were extracted. Emergent themes were identified from the data, defined and reported through an iterative process of theme development.

The primary data coder was KES. Specialist software was not used. To address issues of analytical rigor and trustworthiness, a subset of transcripts were double-coded by KB. A re-iterant process of discussing areas of agreement and disagreement took place between KES and KB to achieve consensus. Alternative interpretations were incorporated in the analysis. The analysis was further tested during discussions with colleagues, and meetings of the project advisory steering group. We also paid attention to non-confirmatory cases where emerging themes contradicted more common ideas. Quotations were chosen to illustrate the themes, and to include a range of study participants.

Results

Four themes were identified from the interview transcripts, each including two sub-themes. Participants were divided between those who cited mainly benefits of integrated care pathways, and those who talked about potential harms. In addition, integrated care pathways for dying appeared to have a symbolic value, acting as a signal that the focus of care had changed. Underlying this were comments relating to the context and infrastructure within which care was provided (Figure 1).

The benefits of integrated care pathways for the dying

Processes of care

Many participants cited benefits of integrated care pathways for dying with respect to processes of care. The LCP provides a structured single record with prompts to guide care, and nursing staff in particular appeared to value the structure that integrated care pathways provide. There was frequent mention of improved clarity about the care which was to be provided.

'I think perhaps it does mean that everybody has a clear picture as to what we are doing and not doing.' (senior nurse)

Integrated care pathways were felt to make care of the dying more consistent and comprehensive, and were felt to be particularly valuable in situations where continuity was compromised, for example out of hours or when turnover of staff (medical or nursing) was high.

'The biggest challenge I find as a nurse is not really knowing where you stand sometimes with treatment with, you know, perhaps the weekend…that's why I think the pathway is a good thing because it gives people guidance and gives us nurses something to follow.' (senior nurse)

An extreme view was that integrated care pathways for end of life care could provide a substitute for face-to-face handover between health care professionals changing shifts.

'So having a form …can make sure that everybody involved can see where you are, what your aims are and what the plan actually is, …rather than having to, to discuss the plan for 10 minutes and tell the new person, you know… if there's a form then everybody can just see, sort of what we're doing' (senior ICU doctor)

From many study participants there was a sense that integrated care pathways provide absolute clarity about processes of care. Much of the language used was of process and protocol, rather than uncertainty or grey areas.

'so it's clear on every patient this is what we're going to do, this is the process' (junior nurse)

Influence of health care provider experience

Several participants thought integrated care pathways for dying people were particularly beneficial for the more junior or inexperienced healthcare professionals. Again, this was particularly related to processes of care: care pathways provided clarity and structure to the care delivered.

'…but I think it provides clear guidelines, in my experience, for junior staff to follow and it is very clear and easy to follow and I think it provides a nice framework.' (junior doctor)

However, a minority of interviewees expressed a different view: that integrated care pathways may be particularly poorly used by inexperienced staff. For example a consultant surgeon spoke about care pathways being used too rigidly by inexperienced colleagues.

'I think pathways ... give some kind of guideline which is helpful for people but often it is particularly young colleagues, it is something which makes them more inflexible... in the way that the most important thing if you work with pathways is to identify patients who don't fit in to the pathways because otherwise you make wrong decisions based on your pathways.' (senior surgeon)

The potential harms of integrated care pathways for the dying

Patient outcomes

In this study it was uncommon for staff members to talk about the impact of integrated care pathways on patient outcomes, and no participant spoke about integrated care pathways as improving the quality of patients' deaths. Where outcomes were discussed, these related to the potential for harm. The words 'dangerous' and 'danger' were used. Integrated care pathways were not thought to be intrinsically bad, but were susceptible to poor use.

The distinction between processes of care and patient outcomes was highlighted clearly by one participant.

'but it is documentation so it doesn't do the care for you, … and there's still an awful lot of thought and…work that you know needs to go into giving that care, … so it's not a tick box exercise, … and I think there's just a danger of that' (senior nurse)

Tick-box care

Several study participants expressed concern that end of life care needs to be individualised, and that the structure of integrated care pathways, which in the case of the LCP included 4 hourly and 12 hourly prompts, can inhibit the necessary flexibility required to provide good care to the dying. One participant spoke about integrated care pathways promoting tick-box care and inhibiting thoughtfulness.

'Whatever care pathway there is, I'm always worried about people switching off their brains. Tick-boxing. Putting down on paper what they have to to fill in the paperwork.' (senior ICU doctor)

Another participant with extensive experience in palliative care spoke about the tension between providing holistic end of life care and following a pathway, and suggested that integrated care pathways may absolve healthcare professionals from clinical decision making.

'I think it's dangerous at the moment at times because that clinical decision-making doesn't happen, it isn't documented and in some instances the pathway, and that's not the intention of the pathway and the people who developed the pathway, but the presence of the pathway, the options of the pathway actually seems to absolve people from that.' (senior physician)

The symbolic value of integrated care pathways

A signal

Several participants described integrated care pathways for end of life care in a way that suggested a symbolic value. Pathways were considered to be a useful signal, even before the paperwork was filled in, to herald the change in focus of care from active to palliative treatment. For example, the presence of the paperwork at the bedside was described as a non-verbal form of communication that the focus of care had changed.

'When it does become a focus issue we very quickly get the paperwork out of the stationery cupboard and put it there [by the bed].' (senior nurse)

A change in focus

The availability of integrated care pathways for end of life care was felt to have a value in legitimising death as an outcome in hospital, providing an acceptable alternative to aggressive medical care. One ICU consultant spoke about integrated care pathways providing a positive focus to the change in patient care by highlighting the care which will be provided, rather than aspects of care that are thought no longer appropriate.

There was a sense, however, that the use of integrated care pathways may promote a binary attitude towards dying: integrated care pathways are either used or not used, therefore patients are either dying or not dying. This perceived clarity regarding the change in focus of care may give some clinicians permission to distance themselves from the patient's care entirely. One senior physician talked about 'switching off' when the LCP is used.

'I always joke about departments where, yes, the Liverpool Care Pathway is used in the department, do you know exactly what happens, by that stage you've switched off and you've handed the patient over, I think that's the honest truth.' (senior physician)

Infrastructure

Education and training

Education and training in palliative care were commented only occasionally. A few study participants volunteered that they had received palliative care training, and for those who had, this had often focused more on how to use the LCP paperwork than generic palliative care skills. For one participant, the LCP itself appeared to act as an educational tool.

'things like the Liverpool Care Pathway and things like that, I think they are a distillation of what I personally have been taught piecemeal over 10, 11 years now since graduation, and even before.' (senior ICU doctor)

Evidence

Only one study participant spoke about the evidence base for the LCP. This participant expressed concern about the lack of strong evidence of the benefits of the LCP, and the lack of awareness among other medical colleagues about the paucity of evidence.

'…there is no evidence. It's not a validated tool' (senior physician)

The four main themes outlined above are illustrated in Figure 1. The focus of this study was to determine health care professionals' perceptions of benefits and / or harms of integrated care pathways for care of the dying, and individual participants were divided into those who cited mainly benefits, and those who cited harms. Central to understanding these experiences are the wider context in which integrated care pathways were implemented. An infrastructure inadequately supported by evidence and education may have paradoxically led to inflation of their symbolic value, and this in turn allowed shortcomings in evidence to be overlooked.

Discussion

This study demonstrates that in the years preceding the Neuberger review, health care professionals were conscious of both benefits and harms of integrated care pathways for end of life care. The benefits related to streamlined processes of care, and were experienced by the health care professionals themselves. Potential harms related to applying the pathway inflexibly or without thinking, leading to poor clinical decision-making, and were reminiscent of criticisms subsequently published by the media and the Neuberger review.

It is notable that no participant in this study cited benefits regarding improved outcomes for patients. This does not mean that integrated care pathways do not have the potential to improve the quality of patients' end of life care, but it does suggest that health care professionals using them may lose sight of the ultimate goal of care: a good death for the patient and improved outcomes in bereavement for their carers. The LCP audits, which measured success of implementation based on process measures not patient-centred outcomes, may have reinforced this.[20]

The LCP was not intended as a protocol, but as a guide.[21] We found that it was often interpreted as a protocol, and moreover for many staff members, particularly the more junior clinicians, this aspect was particularly valued. This may be because for many staff training and education in palliative care had been fragmented and unsystematic, for example focussed on documentation or provided 'piecemeal' over years. It was the more senior clinicians who identified potential harms of integrated care pathways in this study, including relying on them too heavily as protocols. This may reflect their more extensive clinical experience, and overall responsibility for patient care. Integrated care pathways are not a substitute for skills, knowledge or expertise, but there may be a tendency for professionals, particularly those most junior, to interpret them as such. The importance of specialist palliative care team support and specialist training when implementing integrated care pathways for end of life care was highlighted in the first randomised trial of the LCP, published six months after the Neuberger review.[2223]

Although the LCP was intended simply as a guide to care, it fulfilled additional roles. An integrated care pathway for end of life care acted as a symbol to herald the change from curative to palliative treatment, to signal to others that the focus of care had changed, and to legitimise that change. Indeed, for some clinicians the perceived clarity of this switch in the focus of care appeared to allow them to distance themselves from the patients' care entirely.

One of the main criticisms made by the Neuberger review was the lack of prospective testing of the LCP. It is interesting that only one health care professional in this study cited the importance of knowing the evidence base for such a pathway. Professionals may consider research evidence less important or relevant when people are dying, and this may be compounded by the historical paucity of research funding for palliative care.[24] Patchy education and training in palliative care may have created a vacuum that allowed a tool for which there was no strong evidence to become accepted and valued. The strong symbolic value of the LCP may, in turn, have made it easier for professionals, as well as institutions and policy makers, to overlook the shortcomings in evidence (as illustrated in Figure 1).

The strengths of this study are that a large number of people were interviewed, from different grades within several medical, surgical and allied specialties. By using data collected in 2009, we are able to understand the views of health care professionals in the period before the media controversy and Neuberger review.

This study has limitations. The original study focussed on dying in the ICU, where rapid changes in health status and prognostic uncertainty are common. The disproportionately large number of staff members from the ICU in this study may therefore not be representative of the wider clinical setting. Attitudes towards integrated care pathways for end of life care was just one part of the original study and the interview schedule.

This study has important implications for the future development of interventions to improve end of life care. First, it demonstrates the importance of collecting, reporting, and using qualitative data during the development of complex interventions.[25] All interventions have benefits and harms, some of which may be obvious, others less so, especially when the intervention is complex.[26] Collecting such data, including patient, carer, and health care professional perspectives, during the early implementation of an integrated care pathway for end of life care would enable it to be refined and improved.

Second, the study emphasises the importance of investment in education and training in palliative care. The enthusiasm for what was perceived to be a protocol for end of life care indicates a need for improved understanding of how to care for the dying. Without these generic skills, it is unlikely that staff members would be able to use any such tools well, or to recognise when they are being used poorly.

Third, the study identifies the importance of grounding the development of any future tools to improve care of the dying around patient outcomes, not just processes. Measuring processes of care is often more straightforward than measuring outcomes. However, reliance on process measures not only meant that it was impossible to demonstrate whether the LCP improved quality of care for patients and families,[10] it may also have contributed to the staff who used it losing sight of the overall goals of care. Re-orientating health care professionals from processes to patient-centred outcomes is necessary to improve end of life care.

Competing interests

We declare that we have no competing interests.

Authors' contributions

IJH, WP, JK, PH, SL, WB and MM planned the original study, wrote the protocol, won funding, and oversaw the original study. KES, KB, JK and IJH designed, planned and carried out analyses for this paper. IJH, WP, JK, PH, SL, WB, RB, OD, JN and MM formed the Project Advisory Group. KES drafted this manuscript and revised it in response to critical revisions from all authors. IJH and KES are the co-guarantors of the study. All authors read and approved the final manuscript.

Funding

This paper presents independent research funded by the National Institute for Health Research (NIHR) under its Research for Patient Benefit (RfPB) Programme (Grant Reference Number PB-PG-0107-12109). The Collaboration for Leadership in Applied Health Research and Care (CLAHRC) South London is part of the National Institute for Health Research (NIHR), and is a partnership between King's Health Partners, St. George's, University London, and St George's Healthcare NHS Trust. This report is independent research funded by the National Institute for Health Research Collaboration for Leadership in Applied Health Research & Care Funding scheme. The views expressed are those of the authors, and are not necessarily those of the National Health Service, the National Institute for Health Research, the NIHR, or the Department of Health.

Acknowledgements

We are grateful to Dr Cathy Shipman (CS) who contributed greatly to the original study.

Figure legend

Figure 1: Model of health care professionals' perceptions of the benefits and harms of integrated care pathways for end of life care

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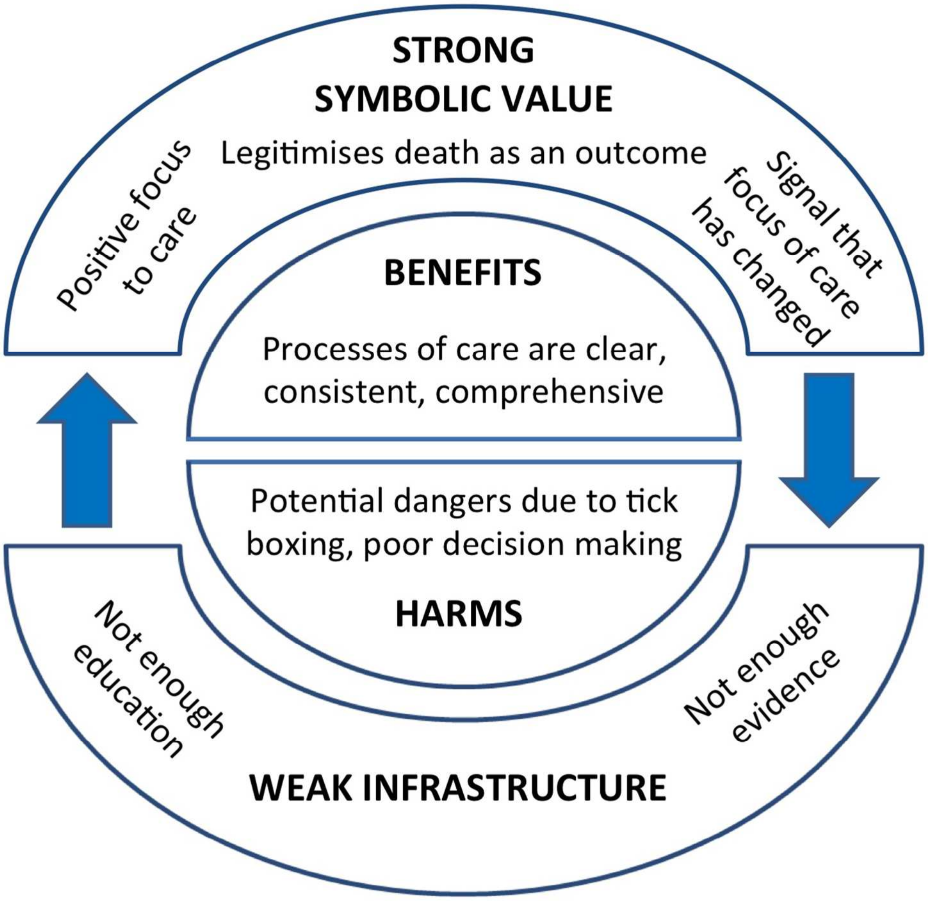

Figure 1: Model of health care professionals' perceptions of the benefits and harms of integrated care pathways for end of life care
498x483mm (300 x 300 DPI)

COREQ checklist,[1] including manuscript page number

'It doesn't do the care for you': a qualitative study of health care professionals' perceptions of the benefits and harms of integrated care pathways for end of life care

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	4. Gender Was the researcher male or female?	1
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Relationship with participants	6. Relationship established Was a relationship established prior to study commencement?	7
	7. Participant knowledge of the interviewer What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	7
	8. Interviewer characteristics What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	7
Domain 2: Study design Theoretical framework	9. Methodological orientation and Theory What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	8
Participant selection	10. Sampling How were participants selected? e.g. purposive, convenience, consecutive, snowball	7
	11. Method of approach How were participants approached? e.g. face-to-face, telephone, mail, email	7
	12. Sample size How many participants were in the study?	7
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Setting	14. Setting of data collection Where was the data collected? e.g. home, clinic, workplace	7
	15. Presence of non-participants Was anyone else present besides the participants and researchers?	7
	16. Description of sample What are the important characteristics of the sample? e.g. demographic data, date	7
Data collection	17. Interview guide Were questions, prompts, guides provided by the authors? Was it pilot tested?	7
	18. Repeat interviews Were repeat interviews carried out? If yes, how many?	7
	19. Audio/visual recording Did the research use audio or	7-8

	visual recording to collect the data?	
	20. Field notes Were field notes made during and/or after the interview or focus group?	7
	21. Duration What was the duration of the interviews or focus group?	7
	22. Data saturation Was data saturation discussed?	8
	23. Transcripts returned Were transcripts returned to participants for comment and/or correction?	8
Domain 3: analysis and findings Data analysis	24. Number of data coders How many data coders coded the data?	8
	25. Description of the coding tree Did authors provide a description of the coding tree?	8
	26. Derivation of themes Were themes identified in advance or derived from the data?	8
	27. Software What software, if applicable, was used to manage the data?	8
	28. Participant checking Did participants provide feedback on the findings?	8
Reporting	29. Quotations presented Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number	8-13
	30. Data and findings consistent Was there consistency between the data presented and the findings?	8-13
	31. Clarity of major themes Were major themes clearly presented in the findings?	8-13
	32. Clarity of minor themes Is there a description of diverse cases or discussion of minor themes?	8-13

1. Tong A, Sainsbury P, Craig J: Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care 19:349-57, 2007