Barriers to implementing an integrated care pathway for the last days of life in nursing homes

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Abstract

Aim: This paper explores the barriers that needed to be overcome during the process of implementing an integrated care pathway for the last days of life as a way of developing quality end-of-life care in nursing homes.

Methods: An action research methodology underpinned the study. Qualitative and quantitative data were collected in eight nursing homes before, during and after the implementation of the care pathway.

Findings: Six main barriers were identified: a lack of knowledge of palliative care drugs and control of symptoms at the end of life; lack of preparation for approaching death; not knowing when someone is dying or understanding the dying process; lack of multidisciplinary team working in nursing homes; lack of confidence in communicating about dying; some nursing homes are not ready or able to change. These findings highlight a functional ‘rehabilitative’ culture that may not be so appropriate in the current context of nursing home care, and one that makes implementing an integrated care pathway for the last days of life less straightforward than in other settings.

Conclusion: It cannot be presumed that the implementation of a care pathway for the last days of life in nursing homes is straightforward. This study suggests that an action research framework was extremely useful in highlighting and overcoming some obstacles when developing evidence-based practice. Action at both local and public policy level is required to fully address barriers that prevent quality end-of-life care in nursing homes.

Nursing homes are increasingly becoming the place where older people die. One in five people in England and Australia and one in four people in the United States currently die in nursing homes (Teno, 2003). There is a growing body of evidence which suggests that dying older people experience unacceptable levels of suffering as a result of widespread under assessment and under treatment of their problems and lack of access to palliative care (Seymour and Philp, 2001; Davies and Higginson, 2004).

Several studies have shown that there is a lack of palliative care knowledge and skills among staff in nursing homes, compounded by a lack of resources, staff shortages and a high staff turnover (Ersek et al, 1999; Komaromy et al, 2000; Forbes et al, 2001).

There is a need to address the quality of end-of-life care in nursing homes but there is a lack of evidence from implementation research on how to get established evidence translated into practice (Davies and Higginson, 2004). This paper outlines the difficulties experienced when an adapted version of the Liverpool Care Pathway for the dying (LCP) was implemented in eight independent nursing homes as part of an action research project to develop high quality end-of-life care in nursing homes. It also discusses how an action research approach helped to address some of these difficulties.

Background

The LCP was developed by specialists in cancer palliative care through a review of the specialist literature in response to the recognition that there is too often unrelied suffering at the end of life in settings other than hospices (Ellershaw and Wilkinson, 2003). It is part of a growing movement to share the lessons learned from specialist palliative care for people with cancer with those caring for people dying from other causes in other settings.

The LCP is a multiprofessional document that focuses on holistic care during the dying phase and provides an evidence-based framework for practice development. It is also a means by which the quality of end-of-life care can be measured. Such a document provides guidance on different aspects of care including the anticipatory prescribing of medication and discontinuation of inappropriate measures, as well as psychological and spiritual care.

Educational initiatives to help staff working in nursing homes to care for dying residents have found that educa-
tion on its own is insufficient to develop practice in relation to end-of-life care (Froggatt, 2000). Facilitating practice development using evidence-based guidelines such as the LCP (Kitson et al, 1998; Rycroft-Malone et al, 2004) may be one way in which development around end-of-life care in nursing homes might be achieved alongside more classical educational initiatives.

The study
The stimulus for this study arose out of a larger 5-year action research project called the Bridges Initiative to develop practice around high quality end-of-life care in nursing homes (Hockley et al, 2004). The final phase of this project was to take an adapted version of the LCP, which had been modified by nursing home staff in a previous phase of the project, and implement and fully evaluate it as a tool to promote high quality end-of-life care in eight nursing homes. The types of facilitation used to implement the care pathway are summarized in Box 1. A full discussion of these can be found in the final report (Hockley et al, 2004).

The methodological approach for the 5-year project was that of action research where the emphasis is on research with people in the real world rather than on or for people (Reason, 1989). Action research is particularly suited to identifying problems in clinical practice and helping to develop potential solutions in order to improve practice (Hart and Bond, 1995; Meyer, 2000). This approach was reflected in the implementation of the care pathway when barriers, identified by the evaluator, were acted on by the clinical nurse specialist (CNS)/research fellow in order to try to overcome them, and then re-evaluated in light of that action. This cyclical process culminated in the summative evaluation at the end of the implementation process.

The objectives of the evaluation are shown in Box 2. In addressing these objectives a number of barriers to the implementation of the care pathway in the nursing homes was highlighted and these barriers are the focus of this paper. The summative evaluation of this final phase and the extent to which these barriers were overcome has been reported elsewhere (Hockley et al, 2004, 2005). The time allocated for this final phase was 1 year (October 2003–September 2004).

Participants
All 72 nursing homes in the health authority were invited to volunteer to take part in the study. Fourteen responded and, after visits to each home to discuss the study, eight independent nursing homes agreed to take part. Because of the relatively short period of the study (12 months) certain inclusion criteria for nursing homes were desirable: a degree of stability in staffing; commitment from management; a willingness to examine current practice and implement the documentation; and, where possible, a relationship with one GP practice giving cover for the majority of the residents.

There were three people in the study team: a CNS/research fellow in palliative care with experience of conducting action research in nursing homes; a senior research fellow with wide experience of participatory research and action learning; and a hospice nurse with experience of evaluation research.

Data collection
A variety of data collection methods, both qualitative and quantitative, were used to address the objectives of the evaluation (Box 3).
Ethical considerations
Ethical approval had already been given for the Bridges Initiative but consent was obtained for an extension of the study to eight nursing homes. Particular attention was paid to the concept of process consent in this study with researchers continually checking participants’ willingness to remain involved. In keeping with the democratic and participatory principles of action research the participants were fed back emergent themes for validation and confirmation. The CNS followed up any practice issues that raised concern during the evaluation.

Data analysis
The qualitative data, including field notes taken throughout the study, were entered, stored and analysed using NVivo qualitative computer software (Richards, 2000). Thematic analysis guided the analysis of the qualitative data. A final interpretation was also checked with key champions. Quantitative analysis of the documentary evidence and the audit questionnaire was using descriptive statistics and a Statistical Package for the Social Sciences (SPSS Inc, Chicago, IL) computer software package.

Findings
In conducting this evaluation a number of barriers were highlighted which made it difficult initially to implement the care pathway documentation. These findings, which are drawn from all the sources of data, are described below.

Barrier 1: A lack of knowledge of palliative care drugs and control of end-of-life symptoms
A key feature of quality end-of-life care is the control of difficult symptoms. One of the main features of the initial assessment when commencing the documentation is to discontinue unnecessary medication and prescribe as required (prn) medication in anticipation of any agitation, respiratory secretions or pain. However, at the beginning of the study, there was a lack of familiarity with palliative care drugs among the majority of staff.

‘It’s quite amazing really when you think about it, all the deaths I’ve seen, and that’s a lot, I have never seen [midazolam or hyoscine] prescribed...’
(staff nurse, final group interview).

When the notes of the last five residents to die in each nursing home before the study were reviewed, it was clear that the loss of the swallowing reflex in a dying resident was seldom anticipated and thus, subcutaneous or rectal medication rarely prescribed. Also the prescribing of prn medication in anticipation of symptoms was infrequent.

Nursing homes are not permitted to hold stock drugs unless they are for a named resident; it was often felt that prescribing prn medication was potentially a waste of money as drugs were destroyed if not used. However, the financial implications of this are negligible compared to the unnecessary length of time a resident has to wait if prn medication is not available. The only drug that was occasionally prescribed prn across the nursing homes in the last days of life before the study was oral morphine, whether or not the residents were on a previous opiate analgesic.

Staff also found it difficult to distinguish between pain and agitation. There was an assumption that dying itself was painful, and because of this opiates were used for agitation in the last days, before the implementation of the care pathway. When completed care pathways were reviewed it was clear that agitation was a much more common symptom than pain. Nausea was rarely a problem.

Owing to the lack of familiarity with palliative care drugs and anticipatory prn prescribing, a change to the documentation was made to detail the specific drug, dosage and route to control anxiety, moist respiratory secretions and pain.

Barrier 2: Lack of preparation for approaching death
While staff often knew ‘in their hearts’ that residents would die in the home, there appeared to be a ‘striving to keep alive’ model of care evident at the beginning of the study. One feature of this was the appearance of a fluid balance chart at the...
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The dying trajectory from cancer is much more predictable than that of old age where the progression of chronic disease may in fact disguise the dying process (Forbes, 2001; Lynn and Adamson, 2003). There was a need for staff to think critically about the overall quality of life, and see this within a wider ‘dwindling dying trajectory’ (Lynn and Adamson, 2003).

It was important to acknowledge the indigenous knowledge already within the nursing home context, and for this to be incorporated into the documentation. Indigenous knowledge is local wisdom that is unique to a society, culture or community and is often underused by ‘external’ professionals (Graham and Clark, 2005).

The model of facilitation used in this study with its emphasis on critical reflection and action learning was useful in bringing to light some of this knowledge around death and dying of the nursing home staff. This knowledge was used to adapt the documentation so that it was a better fit for the nursing home context. Despite the complex and often unpredictable dying trajectory of most frail older people, as time progressed, staff did begin to gain an understanding of the dying process and were implementing the documentation appropriately.

If you think about a couple of cases of people who have become very ill and died, before the “care pathway”, you think, well maybe if I had noticed that person, they didn’t want to walk about any more, they didn’t have any energy, if you start noticing these things before... you can do something better.’

(Staff nurse, nursing home, initial group interview).

Barrier 3: Not knowing when someone is dying or understanding the dying process

It was found that imminent death was often not recognized. At the beginning of the study staff at collaborative learning groups and action learning sets often said that they had not had time to start the care pathway documentation because the resident died very quickly. There was also evidence that some GPs lacked skills in recognizing the dying process.

‘... the man that died in there last week, the GP came out and said to the nurse that was on duty, “don’t get yourself all worked up, you’re getting stressed out about nothing”’. He wasn’t out the door 15 minutes and the man had died. And I thought that was ridiculous, his attitude when he came in... he said, “oh, double his antibiotics you are getting in a state about nothing”.’

(Staff nurse, nursing home, initial group interview).

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(Care assistant, nursing home, final group interview).

Barrier 4: A lack of multidisciplinary team working in the nursing home

Using a care pathway for the last days of life assumes that nurses, carers, families and GPs normally come together in order to make a decision that someone is dying — a diagnosis of dying. Such teamwork was lacking in a number of the nursing homes and caused difficulties around end-of-life decision making. Within nursing homes most nurses will know the resident much better than the GP. However, at the
commencement of the study many nurses did not feel comfortable influencing a GP’s decision and would ‘go along’ with what was suggested even to the detriment of the resident.

‘The staff had sent for the GP thinking he would say “enough is enough” and they would then think about the “care pathway”. The first GP came out and started antibiotics and diuretics, which they could not give because the resident was no longer swallowing. They then got another GP out the next day who decided to send the lady to hospital where she died a few weeks later. The resident in question had dementia and had little contact with family. The lady died in an alien environment much to the dismay of the staff."

(action learning set, nursing home).

It became apparent that there was rarely a forum for discussion and decision making that involved nurses, carers, families and GPs. Nursing homes are not like hospices where there are doctors on site most of the time. The nurses are isolated and carry a lot of responsibility for decision making. Persuading GPs to take part in this study was a major difficulty in developing practice in end-of-life care.

‘Getting GPs on board has been very difficult in some practices. They give the impression they are interested but when it comes to it they don’t actually... they haven’t wanted to participate in the information and things that are organized. We find that they don’t even know themselves what they are doing... some practices are very good and others haven’t been very supportive at all.’

(key champion, final group interview)

If there was not a good working relationship with the GP, exacerbated by the fact that as many as seven GP practices covered the medical care of residents in one home, this added to the reluctance to contact a doctor, thus compromising end-of-life care.

Barrier 5: The staff lacked confidence in communicating about dying

Before the study it was found that death and dying was very much a ‘taboo’ subject in the majority of nursing homes. There was considerable fear around talking about dying. Lengthy discussions occurred between staff at the collaborative learning groups and the initial group interviews concerning the hidden nature of death in the nursing home.

‘I think it’s wrong that [residents who have died] are shuffled out the back door, down the back stairs... why is it shuffled under the carpet, does this person not deserve the respect...’

(care assistant, nursing home, initial group interview).

These discussions also highlighted that often when a resident talked to a staff member about dying, the staff member would block the conversation by trying to ‘chivvy them along’. The implementation of the care pathway for the last days of life demands open discussion about death and dying and it requires considerable skill and confidence to discuss whether a resident might be dying. The closed discussion around death and dying was therefore a further barrier to the implementation of the care pathway documentation.

Barrier 6: Some nursing homes were not open and receptive (or ready and able) to change

Developing end-of-life care through implementing a care pathway for the last days of life requires time, a culture of learning, motivation, and management support. However, with the increasing frailty, complex needs and dependency of residents, as well as increased statutory paperwork, many staff found it difficult to give time and energy to developing practice. Problems with recruitment and a high staff turnover is an ongoing problem in nursing homes (Redfern et al, 2002), and this often made it difficult for staff to attend training sessions as the work ‘on the floor’ always took priority.

‘No it’s not been easy... one of the things is, we try and plan meetings and things and getting the staff here, it’s always, you know there are so many time constraints on people here and that’s what’s been really difficult.’

(key champion, final group interview).

The key champions often had to attend the action learning sessions in their own time or not at all if the nursing home was short staffed. It could be argued that with the lack of a learning culture in an organization, staff are less likely to be motivated to change or develop. If they are not in the habit of reflecting on their practice...
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‘The authors suggest that the collaborative learning groups and the action learning sets used in this study, where staff, including untrained carers, are helped to critically reflect, are essential to overcoming barriers and developing sustainable change in practice.’

they may feel that the care they provide is ‘good enough’ and therefore see no need to change.

Discussion

The LCP is one of the tools the Department of Health is using to implement its End of Life Care Initiative (Department of Health, 2004). Studies in other settings have shown that the LCP does improve outcomes, particularly for those dying from non-malignant diseases, but that its implementation is resource intensive (Jack et al, 2003; Jones and Johnstone, 2004; Mirando, 2005). The difficulties experienced in implementing the pathway in the nursing home setting in this study need to be considered by others implementing the tool in nursing homes and perhaps other settings such as the community.

The fact that the nursing homes in this study volunteered to take part suggests that the managers were already aware of the importance of good end-of-life care. Others at the other end of the spectrum may experience even more difficulties and require more help to implement the pathway. Our findings support the assumption highlighted by Froggatt (2001) that implementing models of palliative care practice developed from specialist palliative care into nursing homes is unproblematic. In other words, it can be problematic and the LCP in this case was adapted as part of the implementation process to make it a better fit for the nursing home context. This is not a criticism of the LCP itself but a reflection of the state of end-of-life care in nursing homes and the different culture surrounding death and dying in nursing homes.

The analogy of developing countries may be helpful in thinking about developing end-of-life care in nursing homes. Development agencies have learned that parachuting experts into developing countries to work for people for a limited time is, in the long run, futile. Rather, they have learned that to achieve sustainable change they must work long term with local people, building on their indigenous knowledge and helping them to develop the capacity to address their issues themselves (Graham and Clark, 2005).

It is the same for nursing homes, which have for a long time been under-resourced and isolated. The action research approach of this study ensured that the authors worked ‘with’ the nursing home staff, but the 1-year timescale, the large number of nursing homes involved and the small size of the research team limited the ability to fully address barriers within all the nursing homes in a sustainable way. Nonetheless, there was considerable progress in overcoming the barriers. While this paper has focused primarily on exploring the barriers which were met when implementing the LCP in the nursing homes, the extent to which these barriers were overcome and the impact of the care pathway on end-of-life care in the nursing homes is reported elsewhere (Hockley et al, 2005).

The action research approach has emerged in response to the failure of much research ‘on’ good practice to translate ‘into’ good practice (Sharp, 2005). The authors suggest that the collaborative learning groups and the action learning sets used in this study, where staff, including untrained carers, are helped to critically reflect, are essential to overcoming barriers and developing sustainable change in practice. A fuller explanation of the facilitation used to overcome the obstacles in this project can be found elsewhere (Hockley et al, 2004).

A specific example of the difference that this kind of facilitation can make compared to traditional education is in relation to the issue of getting GPs to collaborate. Looking at the process of implementing the care pathway identified that getting GPs on board was a barrier to implementing the care pathway.

However, a further step was taken at the collaborative learning groups and action learning sets where staff in the nursing homes were encouraged to think of ways of overcoming this barrier. In addition to using their new knowledge about palliative drugs they looked at how they worded requests to GPs, considered assumptions they were making about the GPs, and thought of ways that they could make options more explicit when making decisions about end-of-life care.

This approach proved to be effective in building up trust and getting some GPs to collaborate with nursing home staff in using the documentation. The staff were not given advice about what they should do but learned how to address contextual issues like this themselves. Through this process the staff felt that their contribution to the care of the residents was acknowledged and valued. This is intensive, time-consuming work but in the long run is much more sustainable.
Conclusions
This study concludes that introducing an integrated care pathway for the last days of life into nursing homes is not easy or straightforward. Practice development, in this case using an action research approach to implement the care pathway, was essential for understanding and overcoming barriers, and identifying specific areas requiring development. The reality in most nursing homes today is that they require this level of intense input and ongoing support in order to improve practice around end-of-life care. This level of support is not cheap and while arguments perpetuate about who should be responsible for paying for it, those who suffer are our grandparents, parents and ultimately, in an ageing society that does not value older people, ourselves.

Quality end-of-life care in any nursing home depends on adequate staff, a culture of learning, motivation and management support. If nursing homes are to cope with their escalating responsibilities, then funding bodies must commit themselves long term to practice development in order to build up the capacity of nursing homes to provide quality end-of-life care. Perhaps it is only by ensuring that palliative care for older people in nursing homes is on the public health agenda that nursing homes regarding end of life care. This level of support is not cheap and while arguments perpetuate about who should be responsible for paying for it, those who suffer are our grandparents, parents and ultimately, in an ageing society that does not value older people, ourselves.

Quality end-of-life care in any nursing home depends on adequate staff, a culture of learning, motivation and management support. If nursing homes are to cope with their escalating responsibilities, then funding bodies must commit themselves long term to practice development in order to build up the capacity of nursing homes to provide quality end-of-life care. Perhaps it is only by ensuring that palliative care for older people in nursing homes is on the public health agenda that nursing homes will be given resources that reflect the needs of the residents and staff. The covert discrimination that dying older people currently suffer will then stop.

Key words
- Nursing homes
- End-of-life care
- Integrated care pathway
- Practice development
- Action research
- Death and dying


Forbes S (2003) This is Heaven’s waiting room – end of life in one nursing home. J Gerontological Nurs 27(11): 37–45


Richards L (2000) Using NVivo in Qualitative Research. QSR International Pty. Ltd., Australia


