

EVALUATING EFFECTIVENESS OF THE GSFCH AND LCP IN CARE HOMES

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ABSTRACT

Background: The palliative care needs of older people residing in care homes are not always recognised. Approximately two-thirds of people in care homes have dementia. However, people with advanced dementia are not always recognised as having a terminal condition and, consequently, their end-of-life care needs are not well understood. The Gold Standards Framework in Care Homes (GSFCH) and the Liverpool Care Pathway for the Dying Patient (LCP) (care home version) are advocated to improve the quality of end-of-life care in care homes. However, evidence on the efficacy of such tools to improve outcomes or change practice is lacking. **Aim:** The aim of this research was to evaluate the impact on the quality of end-of-life care of the GSFCH and LCP in care homes with nursing. **Methods:** Qualitative interviews were conducted with 22 bereaved relatives/friends before, and 14 bereaved relatives/friends and six care home managers after, implementation of the GSFCH and LCP into seven care homes with nursing. Content analysis guided by the 7Cs of the GSFCH was conducted. **Results:** Care home staff changed their attitudes about dying. This enabled more informed end-of-life decision-making involving families/friends, staff and GPs. Findings suggest that improvements in care of the dying occurred following implementation of both tools. **Conclusion:** The GSFCH and LCP improve end-of-life care by influencing end-of-life culture, decision-making and practice. **Conflicts of interest:** none

KEY WORDS

Bereaved relatives/friends
Gold Standards Framework
in Care Homes
Liverpool Care Pathway
for the Dying Patient
Nursing care homes

Despite increasing numbers of older people living and dying in care homes, palliative care needs within care homes are not always recognised or supported (Teno, 2003; Brazil et al, 2004; Hockley et al, 2005; Audit Scotland, 2008). Of the 80,000 people who die in UK care homes annually

(Department of Health, 2008), around two-thirds have some form of dementia (Matthews and Denning, 2002) and their needs at the end of life, and those of their families, are not well known (Small et al, 2007). There is evidence to show that residents with advanced dementia who die in care homes are not recognised as having a terminal condition and do not receive care that promotes palliation and comfort at the end of life (Mitchell et al, 2004). Residents with advanced dementia are often transferred to hospital where they receive burdensome and aggressive interventions in the face of death (Hertogh, 2006). A rehabilitative culture of care persists in care homes and results in dying becoming 'peripheral' (Brazil et al, 2004; Hockley, 2006). A palliative care approach, which affirms life and regards dying as a normal process (World Health

Organization (WHO), 2008) may be a more appropriate model of care in care homes (Hockley, 2006). However, ethical decision-making about treatment, particularly in dementia, is demanding. There is also a lack of empirical data and ongoing debate on what constitutes optimal care with regard to issues such as antibiotics and artificial hydration at the end of life (van der Steen et al, 2002; Pinderhughes and Morrison, 2003; Pasman et al, 2005; Helton et al, 2006).

In the UK, recent government health policy has recognised the need for improvements in end-of-life care with the launch of the *End of Life Care Strategy* in England (Department of Health, 2008) and *Living and Dying Well* in Scotland (NHS Scotland, 2008). Both these policy documents recommend the use of end-of-life tools, e.g. the Gold Standards Framework in Care Homes (GSFCH) and the Liverpool Care Pathway for the Dying Patient (LCP), as means to improve care in generalist settings such as care homes. The GSFCH is a multidimensional framework advocated to optimise the care for residents nearing the end of life in nursing

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care homes. It promotes seven important aspects of care, which together enhance a palliative care approach (Figure 1). Key elements of the GSFCH are monthly, multidisciplinary, resident review meetings, completion of a prognostic 'ABCD' register and associated advance care planning, and discussion of resuscitation status (The Gold Standards Framework, 2006). (The ABCD register prompts discussions relating to the likely life expectancy, whether 'years' (code A), 'months' (code B), 'weeks' (code C) or 'days' (code D) and is used in conjunction with a 'care needs matrix' which guides staff to implement the necessary care for each coding.) The target outcomes are improvements in advance care planning, communication, team working, reduced hospitalisations and high-quality clinical care (The Gold Standards Framework, 2006). The LCP, which has been adapted for care homes (Hockley et al, 2005), can work alongside the GSFCH and is a care plan for the last few days of life. It provides goals to be achieved, promoting confident and co-ordinated teamwork (Ellershaw and Wilkinson, 2003). The education associated with the implementation of these tools includes symptom control, comfort care and complex communication skills. Both these tools are underpinned by the principles of palliative care as defined by the World Health Organization (2008) (Table 1).

Families have an important contribution to make in end-of-life care, not least in end-of-life decision-making. Their role becomes increasingly important in the case of residents with advanced dementia who are cognitively impaired (Wetle et al, 2005; Shield et al, 2005; Vohra et al, 2006). Bottrell et al (2001) suggest that regular monthly discussions that aim to identify short- and long-term goals can facilitate family discussions and avoid crisis decision-making. Bern-Klug (2006) also suggests that giving residents and families opportunities to discuss desired and undesired medical care and the residents' options and current health status, helps facilitate discussion about when the dying phase has begun. In addressing these aspects of end-of-life care, the GSFCH and LCP show promise for improving the quality of end-of-life care for all those dying in care homes from all causes. However, there is little evaluation of the efficacy of

such tools to change practice or improve outcomes (Shipman et al, 2008; Walshe et al, 2008; Ingelton et al, 2009) and questions remain about the evidence base supporting their widespread adoption (Ingelton and Froggatt, 2009).

Vohra et al (2006) suggest that family experiences must be listened to in order to sharpen the focus for quality improvement in end-of-life care. Retrospective interviews with bereaved relatives are often used to evaluate the quality of end-of-life care delivered. Relatives are part of the unit of care and their views have validity. They can also comment on the care they have received (Addington-Hall and McPherson, 2001; Aspinall et al, 2003; Thompson and Chochinov, 2006). In March 2007, seven nursing care homes in Midlothian, Scotland, agreed to take part in a project to implement and evaluate the GSFCH and LCP. Quantitative and qualitative data were collected. The quantitative evaluation is reported elsewhere (Hockley et al, 2010). Qualitative research can help to uncover the processes of change and what said changes mean to those involved

(Burns, 2000). This article reports on the qualitative interviews with bereaved relatives/friends and care home managers from seven Scottish care homes.

Methods

This was part of a larger study reported elsewhere (Hockley et al, 2010), carried out to implement and evaluate the implementation of both the GSFCH and LCP in seven care homes with nursing (nursing homes) in one Community Health Partnership in Scotland. The implementation period lasted 18 months (January 2007–June 2008) and was facilitated by an experienced palliative care nurse (JH). Key champions were appointed in each home. These are nurses within the homes who take on the role of 'championing' palliative care and are willing to help change the culture through the implementation of the tools. GPs were contacted through the nurse manager and given information about the project. The facilitator visited each home every 10–14 days. The nature of the contact included: attending monthly GSFCH register meetings alongside GPs; scenario-based teaching on death/



Figure 1. The 7Cs of the Gold Standards Framework (GSF) in Care Homes.

dying when implementing the LCP; role modelling good palliative care as the opportunity arose; facilitating debriefing sessions following a death; helping champions cascade down the 'Foundations in palliative care' educational programme for care home staff (Macmillan Cancer Relief, 2004); and regular meetings with management/champions (Hockley, 2006).

The research aim was to evaluate the impact on the quality of end-of-life care of the GSFCH and LCP in nursing homes. A nurse researcher (first author) based at a local hospice and seconded to the university undertaking this project carried out the qualitative evaluation. Interviews were conducted with nursing home managers after implementation of the GSFCH and LCP and bereaved relatives/friends before and after the implementation. The nursing home managers identified the next of kin of residents who had died and invited them by letter to participate. *Inclusion criteria:* all relatives bereaved within a 6-month period (August 2006 to January 2007) before implementation across the seven homes were invited to take part. Due to differences in the progress of the nursing homes regarding the intervention of the GSFCH and LCP, invitation to relatives to take part in an interview, post-implementation, was phased over a longer period. The first phase invited all relatives bereaved in January and February 2008 from four nursing homes to participate. In the second phase the remaining homes

invited all relatives bereaved in February, March and April 2008 (minimum 2 months' post-bereavement) to participate. The facilitator was still visiting the homes at this stage but all the teaching sessions had been completed. Both pre- and post-implementation deaths in hospital and nursing home were included. All relatives had to be able to read/understand the information sheet and sign the consent form. *Exclusion criteria:* the exclusion criteria for both phases were relatives unable to understand the information sheet and provide informed consent.

A reply slip and a stamped envelope addressed to the nurse researcher were sent to participants. Pre-implementation, 42 relatives were invited to participate. Twenty-two agreed (52%), seven declined and 13 did not reply. Post-implementation, 33 relatives were invited to participate. Fourteen agreed (42%), five declined and 14 did not reply. Interviews with relatives took place from October 2007–June 2008, mostly in the homes of the interviewees. Questions were loosely structured around the 7Cs of the GSFCH (see Figure 1). Examples of questions were: 'Would you like to tell me the "story" of your [relative's/friend's] last year and the last weeks of life? (What went well? What could have gone better?); 'Did you have an opportunity to discuss options for care in the event of your [relative/friend] becoming seriously ill in the nursing home? (What did this involve?); and 'When your [relative/friend] was

becoming poorly, did the staff talk to you about this? How were these conversations? ('Do you remember a particular conversation that stands out?'). Participants were invited to talk about their relatives' time in the nursing home, including the last weeks and days. The bereaved relatives/friends were given a telephone number should they require any support after the interview. Managers were interviewed by telephone. These interviews were also structured loosely around the 7Cs and the managers' experience of being part of the project.

Interviews were digitally recorded and transcribed verbatim with consent. All the transcriptions were anonymised. Initial analysis involved listening to the tapes and reading the transcripts in order to become immersed in the data. NVivo qualitative software was used to facilitate coding, management and retrieval of data. Interviews were analysed using content analysis. The 7Cs (see Figure 1), which guided the data collection, were used as a framework to arrange the initial categories systematically. Overlap between the 7Cs resulted in three emerging overarching themes: end-of-life decision-making; end-of-life care practice; and end-of-life context (cultural and organisational). The analysis process is shown in Table 2. A proportion of the interviews were analysed independently by two of the authors until consensus was achieved. Constant comparison between relatives and nursing homes ensured that the analysis represented all perspectives.

The local medical ethics committee and the owners of the nursing homes gave permission for the study to proceed. The ethics committee considered the project to be an in-depth evaluation of an intervention that was a nationally recommended service improvement. It thus considered it a service evaluation, which it judged should go forward without the need for full ethics application. The LCP used in the project was adapted for use in care homes in a previous project by one of the authors (JH) (Hockley et al, 2005; Watson et al, 2006). Reflexive field notes were kept throughout the current project as a means of raising awareness of, and challenging, bias in this evaluation (Hockley and Froggatt, 2006).

Table 1

World Health Organization's (2008) principles of palliative care

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten nor postpone death
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until death and to help the family cope during the patient's illness and in their own bereavement
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- Will enhance quality of life and may also positively influence the course of illness
- Is applicable early in the course of illness in conjunction with other therapies that are intended to prolong life such as chemotherapy or radiation therapy and includes those investigations necessary better to understand and manage distressing clinical complications

Results

Six managers were interviewed after the implementation of the GSFCH and LCP. This occurred in the final month of the project before the facilitator withdrew. The seventh manager was invited to participate. However, due to work commitments the manager was unable to commit to a date before the project finished. Thirty-six relatives were interviewed, 22 pre- and 14 post-implementation. Bereavement times ranged from 2 to 13 months. Twenty daughters, three sons, one husband, two wives, four nieces, three nephews, one sister and two friends were interviewed. For the purposes of this research, the nursing homes have been given the letters A–G (Table 3). No relatives from nursing home C responded post-intervention and in home E no relatives responded either pre- or post-implementation. The managers' interviews from these homes, however, highlighted interesting contextual issues. The interviews lasted between 30 and 80 minutes. Differences in relatives' experiences pre- and post-implementation are now explored. The experience of nursing home managers is drawn on in an attempt to explain the mechanisms of the change. In reporting the results, relatives/friends have been given a number alongside a code for the applicable nursing home. Reference is also made to whether the interview occurred pre- or post-implementation of the GSFCH and LCP.

End-of-life decision-making: co-ordination, communication and continuity of care

The pre-implementation interviews highlighted that relatives were at times asked to make difficult treatment decisions at a time of crisis, resulting in uncertainty for them and their relative being admitted inappropriately to hospital. These situations tended to occur out of hours with an unknown GP:

‘When we got to the home the doctor said, “the ambulance will be on its way but I can cancel it if you like. Do you want your mum to stay here? Or do you want her to go to hospital?” I said, “well it’s difficult to know, is mum suffering? If she is suffering then we better have her in hospital and see what they can do for her”... I said to him “Is she in pain?” He says, “well I

really can’t tell if she is. This is what I’m trying to find out” [Pre A3].

On arrival at hospital this woman was diagnosed as ‘dying’. She returned to the home where she died the next day. Another example shows a relative unprepared for a difficult decision:

‘It was the GP who actually phoned me and he asked me, what do you want to do? And I thought well, I didn’t understand the question to be honest, because it was such a surprise...he said do you want her to get medical attention? I said well yes, obviously. So it’s a bit strange the way he put it across. I don’t know if I just wasn’t ready for that sort of question. Obviously I was looking for her to get the best attention she could get’ [Pre A4].

After the implementation there was evidence of staff more confidently

and proactively guiding relatives in their decision-making:

‘And Nurse Judy [a pseudonym] talked about the difficulty of moving to a hospital and the unfamiliarity of that and the kind of anonymity and the fact that the staff in the hospital wouldn’t know her and her ways and what she liked and didn’t like...so it made absolute sense to me that she should be in [Nursing home G] if at all possible’ [Post G6].

The quotation below shows a manager’s increased confidence in communicating about dying and the difference that advance care planning and a ‘do not attempt resuscitation’ (DNAR) instruction can make to co-ordinated care and continuity of care out of hours:

‘...NHS24 [service to contact out-of-hours’ doctors] don’t know the people and sometimes

Table 2

The analysis process

Proactive discussion with family about resident's current condition	Communication	End-of-life decision-making
Dealing with issues		
Emotional/spiritual care of the resident		
Named nurse or key worker	Continuity of care	
Place of death		
Advance care planning, do not attempt resuscitation status		
Leadership	Co-ordination	
Contacts with health professionals outwith the care home		
Discussions about death and dying with the resident and family	Care of the dying	
Physical care during and after dying		
Staff recognition of dying		
Attending funeral/saying goodbye	Carer support (staff and family)	End-of-life care practice
Family relationship with staff		
Pre- and post-bereavement care		
Assessment and control of symptoms/frequency of symptoms	Control of symptoms	
Staff knowledge of medication and syringe drivers		
Prescribing of medications at the end of life		
Culture around death and dying	Continued learning	End-of-life context
Staff knowledge of all aspects of end-of-life care		
GP knowledge of medications at the end of life		

Table 3

Nursing home size, ownership and key champions involved

Nursing home	Size of nursing home	Ownership of nursing home	Number of key champions
A	Medium	Corporate	3
B	Large	Corporate	3
C	Small	Family run (multiple nursing homes)	2
D	Large	Corporate	2
E	Small	Corporate	2
F	Small	Family run (multiple nursing homes)	1
G	Large	Corporate	3

that can end up where they say, “have you got a DNAR order” or “have you got any idea of what the wishes are?”, and we didn’t at that point. Where now, yes, we are able to say, we have this, and we have had these discussions and you know, we are able to express what the family and the person would want. It’s much more confident’ [Home A manager].

End-of-life care practice: control of symptoms, care of the dying and carer support

End-of-life care decision-making is linked to confidence in delivering end-of-life care. In the first quotation in the previous section (Pre A3), the GP appears to lack confidence in assessing and managing pain. As a result a decision is made to transfer a dying resident to hospital. There were other similar examples of poor symptom management and review of medication in the dying phase:

*AI: A couple of times she tried to get up but she was sore
Interviewer (I): You think she was sore?
AI: Oh she was sore... yes
I: Where was she sore?
AI: In her back at the base of her spine
I: And was she on painkillers at all?
AI: She was on painkillers yes but I found they were quite big and she had trouble swallowing them. She was on quite a few tablets at that time with the antibiotics and painkillers and I don’t think she could take them all like [Pre A1].*

Before the implementation of the GSFCH and LCP lack of review of appropriate medication was linked to a lack of recognition of the dying phase:

‘She got a chest infection and it happened very quickly. I thought the nursing staff seemed quite unaware of her impending death. And I didn’t see why I should be seeing it and not them. In fact, the night before she died, they were still trying to give her Senokot, oral Senokot. And I was saying to them, I didn’t think it was actually necessary’ [Pre C3].

Another danger of staff being taken by surprise by dying is that relatives are not given the support they require:

‘I don’t think they really expected people to be there when a death took place. I don’t think they were prepared for people hanging around and getting in the way. I think there has to be provision for when people die that you are made at home really. And I don’t think we got a cup of tea the whole time’ [Pre C3].

No relatives were interviewed post-intervention in nursing home C but the manager was able to recognise the difference that using the GSFCH, particularly the ABCD register, could make to the issue of recognising dying:

‘Because, when you are very very busy, and sometimes these changes, the gradual deterioration may pass you by. But when you actually have to sit and focus on, you know, updating the register... you think, oh yes, something has happened there, it’s time to move onto the next stage. And that’s a prompt to say... when I next see the relatives I must make sure we are ready for that and talk it through with them’ [Home C manager].

Some nursing homes were using the LCP by the end of the project. One relative seemed bemused by it:

‘I was a bit puzzled... it’s almost as if they were following a textbook... which seemed maybe a little academic... I’m sure every person is slightly different’ [Post G4].

Nursing home A adopted the LCP early in the project and it quickly became embedded in its practice. The manager was very positive: ‘Everyone has seen the benefits of it.’ A relative highlighted how it helped communication in the last days:

‘It seemed very good to me... I think it certainly keeps you very much in the picture’ [Post A2].

There were more examples of good physical care in the dying phase at the end of the project:

‘But as to when she was dying and when she died, the care was definitely excellent. They made her comfortable... her bed was changed every single day. She was changed, she was washed, you know given a bed bath and everything was done for her’ [Post D3].

End-of-life context (cultural and organisational): continued learning

At times the culture within the homes around death and dying was a barrier to them recognising the dying phase:

‘We have a large number of nurses [from overseas] and one of the biggest challenges for them was the idea that you could actually have a planned death. Because in their culture you do everything you can to sustain life... so that was a bit of a challenge there for them to understand that there was a time to die... that we weren’t assisting death but planning for the inevitable’ [Home B manager].

This attitude contrasted with that of relatives:

‘Nurse Sally [a pseudonym] was a person [who thought] that a person’s life should be prolonged regardless... and she had said that as long as she was on duty she’d be making my mum eat and not just have her doped up and passed away. Which I thought was not the way, if I had chosen for my

mum to pass peacefully, she should really have been left peacefully' [Pre B2].

Even in those homes where care of the dying was very good, there was still an attitude among staff of not wanting to acknowledge that a resident was dying, even when relatives did:

'She took a turn...and she just deteriorated and the eating had gone right back. But they were so positive, you know, we'll get her right...they were hoping they would get her eating again...I thought, she's not going to get over this and my daughter saw the deterioration as well' [Post F1].

The manager of this home was able to reflect how her learning as a result of being part of the project, over time, was beginning to change her attitude to dying. It was also helping her recognise the difference between palliative care which promotes comfort and futile interventions:

'Whereas before I would always persevere with antibiotics, I always had an element of, oh there could be hope, there could be hope. And I was just really going through false hope then. So realistically there's areas in it where I have become more aware of situations which only really prolong the dying process instead of giving the resident their dignity that they deserve at the end' [Home F manager].

Care staff were also starting to value the idea of a good death as something to aim for rather than fear:

'Now...they've seen it coming, they're prepared for it, they've seen the resident preparing for it and the family and by the time they get to the dying stage they are like, well didn't she go comfortable...didn't she look nice, she looked peaceful...you are getting that kind of attitude now where before it was more a frightened panic state they were in' [Home E manager].

Before the implementation of the GSFCH and LCP there was evidence of a lack of training in care of the dying:

'...I was never away from the place because I didn't actually feel comfortable that they were doing their job properly. And you know what it was? They didn't understand.

The younger carers hadn't been taught properly. And the senior carers they hadn't been taught properly either...they wouldn't position him properly...his oral hygiene wasn't being met' [Pre G2].

Examples of poor care such as this were much less evident in interviews with relatives post-intervention. However, care was not always consistently good. The use of bank staff that were not part of the training contributed to this lack of consistency. This is illustrated in the quotation below which relates to a resident 3 weeks before her death:

'There was one Sunday I was in and it was a different nurse that was on...a bank nurse...my mum was in her bed and she was really distressed and I said to her "I really think my mum needs a doctor". And she says "I'll decide"...and I wasn't very happy. And I said well I thought if a person is really unwell it is better to ask the person...I woke mum up and asked her how she was feeling. I says she's feeling absolutely rotten. I says she's frozen cold and she isn't looking well at all. And she did phone NHS24 eventually but she wasn't very happy about it...it was obviously, couldn't be bothered, but she was just bank staff' [Post D4].

Maintaining consistently high levels of care, skills and knowledge poses an ongoing challenge in the nursing home setting, despite programmes such as the one described:

'You seem to be in a constant cycle of training without any consolidation or application... four of our carers this year who did VQ2 [vocational qualification level 2] training and participated in all the palliative care training that was going...at the end of it, when they have got that, it makes them a very attractive proposition to the NHS and everybody else who can pay up to £2 an hour more than we can' [Home C manager].

Despite the challenges, all the managers felt implementing the GSFCH and LCP had been worth the effort:

'It is time consuming at the beginning. And it is a challenge to take on, to change everything around about in your staff team and to get them all to understand. But I would advise any home to take on this kind

of training and use it in their home because I think, in all my years in nursing; this has been the most beneficial in palliative care that I have seen. I think it is excellent care' [Home E manager].

Discussion

The results presented here are part of a larger study that showed an increase in DNAR documentation and advance care planning and a reduction in unnecessary hospital admissions and hospital deaths following implementation of the GSFCH and LCP in seven care homes with nursing (Hockley et al, 2010). These results are in line with a previous large evaluation of the GSF in the care home setting (Badger et al, 2009). However, it is advised that care should be taken when considering simple end points such as a reduction in hospital admissions as it cannot be assumed that all hospital admissions are inappropriate and that a reduction in them necessarily reflects better clinical decision-making (Ingelton and Froggatt, 2009, Ingelton et al 2009). In this project, a judgment of 'inappropriate' was based on clinical criteria by an experienced palliative care nurse. This article, in reporting on qualitative interviews with bereaved relatives/friends and nursing home managers, highlights the complexity of end-of-life care outcomes such as a reduction in inappropriate hospital admissions. It also provides rich insights into the mechanisms by which the GSFCH and LCP can change practice and have an impact on end-of-life care.

Good end-of-life decision-making is a prerequisite for effective end-of-life care, both of which are strongly linked to and influenced by the organisational and cultural context in which they take place. The evidence presented here confirms family involvement in end-of-life decision-making. Treatment decisions related to nutrition and hydration, transfers to hospital, the use of antibiotics and resuscitation are highly emotional as their outcome could be a matter of life or death (Caron et al, 2005). As Forbes et al (2000) show, families often do not know where their relative is on the disease trajectory and do not feel equipped to make these decisions. They require good communication with a consistent healthcare provider and explanation to understand the disease trajectory, explore

values and goals and reduce confusion, burden and guilt.

Results presented here show that monthly meetings using the ABCD register and the education that goes alongside introduction of the GSFCH can help staff to understand better the dying trajectory, be more alert to signs of decline in residents and prompt them to communicate any changes with relatives/friends. This can help staff become better guides for families when difficult and emotive decisions need to be made. This in turn can help avoid unnecessary hospital transfers and hospital deaths (Travis et al, 2001). If the process of advance care planning, as part of the GSFCH, is initiated on admission to a nursing home, it could help establish a trusting and supportive relationship that is so important to families when their relative is eventually dying. Although not all relatives grasped the significance of the LCP, in homes where it was embedded in practice early, such as Nursing home A, there was some evidence to show that it helps to maintain the communication process during the dying phase. Other studies have shown that the LCP can enhance communication with relatives and within the team (Hockley et al, 2005; Mirando et al, 2005; Gambles et al, 2006). Evidence shows that good teamworking contributes to a 'good death' in nursing homes and that families should be considered part of the team (Hanson et al, 2002). The results presented here demonstrate how the GSFCH and LCP can provide a mechanism which ensures that there is an agreed plan of care, thereby promoting teamwork and continuity of care within the home and also with health professionals who bear responsibility from outwith the home.

Caron et al (2005), in their study of the experience of family caregivers in end-of-life decision-making, showed that concordance of values can facilitate decision-making. They found that when health professionals agreed with family decisions, end-of-life moments were easier and negative feelings such as guilt about ceasing treatments were reduced. The results of the present study show that before implementation of the GSFCH and LCP, this was not always the case in the nursing homes involved in this study.

Some staff were unable to regard dying as a normal process, in contrast to some families. However, evidence from managers shows that through being involved in the study, attitudes were changing and people were beginning to recognise and accept the difference between palliative care, which promotes comfort, and futile interventions, which could potentially prolong suffering. This suggests that implementation of the GSFCH and LCP promotes a change in culture towards a palliative care approach. Such a culture, alongside a systematic approach using the ABCD register, increases the likelihood of recognising dying, leading to better care and carer support. Hertogh (2006) suggests that advance care planning alone is not enough to guarantee the quality of end-of-life care. A reduction in unnecessary hospital transfers must be matched with high-quality end-of-life care in the care home. In this study, interviews with bereaved relatives before the implementation highlighted a lack of knowledge about the control of symptoms and aspects of delivering care to dying residents. In post-implementation interviews, less negative experiences were shared, suggesting that the educational component of the GSFCH programme had improved care in the dying phase.

Study limitations

The timing of the interviews was constrained by the progress made in the nursing homes and the finishing date of the project. Each home completed the training and began to implement the various parts of the GSFCH and LCP at different rates. It is unlikely that the project had fully embedded in some nursing homes by the time that relatives were interviewed post-implementation so this article may not give a complete picture of the impact of the intervention. The project's time limitations and the fact that the qualitative evaluator only worked one day a week on it meant that telephone interviews were easier to arrange within the busy schedules of the home managers. This may have compromised the establishment of rapport and the ability to pick up on visual cues (Bryman, 2001).

Recommendations for future research

Further research is required into the support needs of families whose relative

is dying in a care home. The development and maintenance of good relationships between relatives, staff and residents, especially those with advanced dementia at the end of life, requires further exploration. A better understanding of ways in which the GSFCH and LCP can facilitate this would be beneficial.

Conclusion

In this article, interviews with bereaved relatives/friends and nursing home managers highlight some of the mechanisms by which the GSFCH and LCP can bring about changes in end-of-life care. An increased use of advance care planning involving discussion of DNAR and the ABCD register enabled more confident and appropriate end-of-life decision-making among staff, families and GPs. A factor contributing to this was a changing attitude towards death and dying, i.e. dying being increasingly recognised as a natural process, futility of certain treatments being acknowledged, more concordance between the views of staff and relatives, and less fear of death among staff. These factors may explain the reduction in unnecessary hospital transfers and hospital deaths highlighted by the quantitative evaluation (Hockley et al, 2010). Relatives/friends talked less about poor care and symptom management after the tools' implementation, suggesting that there were improvements in this regard. Fundamental shifts in attitudes about dying take time and account for much of the 'work' of the implementation of end-of-life care tools. Sustainability of these changes in a context with an unstable workforce requires ongoing support and education. **EOLC**

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Key Points

- ▶▶ High-quality end-of-life care (EoLC) is not delivered consistently in care homes.
- ▶▶ The Gold Standards Framework in Care Homes (GSFCH) and the Liverpool Care Pathway for the Dying Patient (LCP) (care home version) can improve the quality of EoLC in care homes.
- ▶▶ More evidence and understanding is needed of how and to what extent the GSFCH and LCP can improve the quality of EoLC.
- ▶▶ This study suggests that implementation of the GSFCH and LCP in care homes increases the likelihood of staff recognising dying, leading to better care and carer support.