Raising standards for elderly people dying in care homes

Older people have been termed the 'disadvantaged dying', and for good reason, say **Frances Badger**, **Keri Thomas** and **Collette Clifford**, who look at a new pilot programme for care homes to ensure better standards of end-of-life care

In the UK, dying is increasingly experienced in old age and almost 85% of deaths occur in those aged over 65.[1,2] Most older people die from non-cancerous illnesses, and multiple morbidity is the norm. However, palliative care in most of Europe has focused on those dying from cancer, and there has only been a slow recognition that age-related illnesses such as dementia have implications for end-of-life care.[3]

Residents in care homes require skilled end-of-life care because, by nature of their underlying illnesses and disabilities, they may be less able to communicate their views and wishes. Relatives and staff may act as advocates, though their wishes may differ. The combined effects of limited access to specialist services,[4] experience of co-morbidities, repeated hospital admissions, lack of advanced planning and under-recognition of symptoms result in older people being described as the 'disadvantaged dying'.[5]

Key points

- In the UK, 4% of older people live in long-term care and form the majority of those living in care homes. In England and Wales, a fifth of those aged over 65 will die there.
- Research has shown that care home staff of all grades have training needs in relation to end-of-life care.
- The Gold Standards Framework in Care Homes (GSFCH) is one example of a programme to improve end-of-life care in nursing homes by offering staff training and a framework to help identify, assess and deliver care.
- The evaluation of the phase two programme indicated demonstrable improvements in the quality of care at the end of life in homes that were able to adopt this approach.
- Key improvements included better care planning, communication, staff confidence, collaboration with others and significantly reduced crisis hospital admissions and a reduction in hospital deaths.

Nursing homes

Four per cent of older people in the UK live in long-term care and they form the majority of those living in care homes.[6,7] Approximately 42% of older people in care homes in England are in nursing homes, and the remainder are in personal care homes.[8] In England and Wales, a fifth of those aged over 65 die in care homes, a figure that rises to more than a third in the over-85s.[2] Clearly, optimal standards of end-of-life care are essential, yet despite the numbers dying in care and the trend for people to be transferred to nursing homes at the end of their lives, there is still relatively little emphasis on the needs of older people dying in these settings.[5,9]

A decade has passed since the first major study of end of life in care homes acknowledged that quality of dying was an important area, mapped out the context and concerns and made recommendations.[10] Two fundamental factors were acknowledged in shaping the provision of end-of life-care in homes, namely relationships and resources.[11] Although more education is now provided in care homes, the increasing dependency of residents and their complex care needs mean that more education is still needed.[12] Recent research indicated that older residents do not report pain.[13] This has implications for end-of-life care, illustrating the need for pro-active and skilled pain assessment by staff.

Positive features of dying in a care home compared with dying in a hospital have been identified, including staff knowing residents and their families, and a less clinical

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atmosphere. Challenges also exist though. These include lack of access to specialist palliative care and variable access to community services.[4] Other challenges include advance care planning, ensuring staff are aware of each resident's wishes should their condition deteriorate and anticipatory prescribing and pre-planning of care. While nursing homes have qualified staff, much of the caring work is carried out by unqualified, though not necessarily untrained, staff and it is vitally important that training reaches all staff groups.[14]

Death may be regarded by practitioners as a failure of medical care, but within nursing homes dying is part of the normal sequence of events and most residents are aware they will die in the home.[15,16] Nurses are in an ideal position to open up discussions about the end of life, but research in hospitals suggests that they may lack the confidence and skills to communicate effectively in these situations.[17–19]

Programmes to improve end-of-life care

Programmes to improve care in nursing homes have adopted a number of approaches including improving palliative care support, implementing staff education and introducing end-of-life care pathways.[20–22] Such interventions have been shown to yield positive outcomes in terms of staff knowledge and skills, but achieving the necessary organisational or cultural change may be more difficult.[21] Staff education is the responsibility of, and is funded by, individual homes or groups and provision may be patchy, though recent improvements in provision have been identified.[12] Educational initiatives to improve end-of-life care in nursing homes have potentially broad outcomes, as the underlying principles that such programmes address are those that staff have identified as important to overall quality of care in these settings.[23]

The Gold Standards Framework in Care Homes programme

One programme that aimed to improve the quality of end-of-life care in nursing homes in England was recently evaluated.[24] The Gold Standards Framework (GSF) programme was developed initially to improve end-of-life care in primary care by supporting GPs and primary care teams to optimise the quality and organisation of care for people in the final year or so of life.[25] (See www.goldstandardsframework.nhs.uk and Box 1, overleaf.) Practitioners' assessments of the primary care programme have been positive and recognition of the importance of nursing homes to end-of-life care resulted in adaptation of the programme.[26] The aims of GSF in general are that:

- People's symptoms will be as well controlled as possible
- People will be enabled to live well and die well where they choose
- People will experience less fear and anxiety, there will be better information, fewer crises and fewer admissions to hospital
- Family carers will feel supported, informed and involved
- Staff confidence, team working, satisfaction and communication will be better.[27]

The Gold Standards Framework in Care Homes (GSFCH) programme was piloted in 12 nursing homes.[28] This indicated its potential impact, the feasibility of wider implementation, the suitability of assessment tools and areas that required further development.

The first large scale roll-out of the GSFCH programme started in June 2005 (phase two) and four staged one-day workshops for staff were held over an eight-month period. Following each workshop, staff implemented the programme in their homes, supported by a range of training materials and local GSF facilitators. Many homes were able to participate in the programme through the NHS End of Life Care Programme funding.

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Evaluation of the GSFCH

An evaluation team, separate from the GSF team, was involved at the start of phase two and homes were told of the evaluation when they enquired about participation in the GSFCH programme. The evaluation had two main elements:

- To establish the feasibility of introducing the programme into care homes
- To identify the structural and organisational factors that supported or hindered implementation of the GSFCH.

Quantitative evaluation included a survey of the care home context and end-of-life care just before the programme started and one year later. An audit of five deaths pre- and post-training programmes ('After Death Analysis') was also completed by each home. The perspectives of managers, staff and residents on end-of-life care were obtained during telephone interviews and case study visits to a smaller cohort of homes. Quantitative data were analysed using the Statistical Package for the Social Sciences (SPSS) and qualitative data were analysed in line with the template approach.[29] Findings from the whole evaluation have been reported elsewhere.[24] The selected results below give an indication of the outcomes.

Results from the second phase

Ninety-five nursing homes signed up to phase two of the programme. Seventy-nine homes returned pre-GSFCH surveys and 49 returned both pre- and post-GSFCH data. Forty-four homes returned data to enable pre- and post-GSFCH After Death Analysis.

For the most part, homes found the GSFCH programme was a positive experience. They had adopted tools to help identify the need for end-of-life care and implement advanced care planning. Post-GSFCH, almost 90% of homes had a register of residents' end-of-life care needs (as against 21% pre-GSFCH) and were using guidelines to help identify residents' needs in order to facilitate care planning. Analysis of residents' deaths pre- and post-GSFCH revealed a reduction in hospital deaths from 18% to 11% after implementation and a decrease in crisis hospital admissions from 38% to 26%.

Good end-of-life care requires collaborative working with primary care, and the GSFCH programme appeared to support staff in establishing better relationships with primary care practitioners. Some difficulties persisted though, particularly in relation to out-of-hours GP services. Staff felt the GSFCH programme raised the profile and importance of well-planned care for dying residents, improved communication between all levels of staff and increased staff confidence in talking to residents, to families and to each other about dying. While improvements in residents' experiences of end-of-life care cannot necessarily be extrapolated from these findings, staff accounts revealed that they felt better prepared to deliver end-of-life care and gave examples of improvements in resident and family care that they attributed to the GSFCH.

Phase two was the first large-scale implementation of the GSFCH programme and development was ongoing. Homes that failed to complete the evaluation were contacted and invited to identify the reasons. Factors related to the GSFCH programme were noted and conveyed to the GSF team, enabling further refinement of the programme.

Using formalised feedback and 'speed-dating' at the workshops, staff identified aspects of the programme or of end-of-life care that were felt to be successful or that required further development. Reflection by the development team and the research team enabled a greater appreciation of the challenges of introducing educational programmes and change into nursing homes, and of the adaptations made.

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Box 1. The Gold Standards Framework in Care Homes programme (www.goldstandardsframework.nhs.uk)

- A structured flexible framework, using a step-by-step approach to improving care for all residents, with four gears and three key tasks at each stage.
- Key goals are to:
  – Improve the quality of care for people nearing the end of life
  – Improve collaboration with GPs and palliative care specialists
  – Reduce hospital admissions and hospital deaths.
- Now developed into a three-stage quality-assured programme over one to two years – preparation, training and consolidation stages, followed by formalised accreditation.
- Based on the GSF programme in primary care and well co-ordinated with it, but fully modified and adapted into a new programme for use in care homes (initially care homes with nursing). Evidence-based, but modified using grass-roots experience and shared learning.
- Currently in phase four, with 600 care homes involved throughout the UK. The GSFCH programme is run only by the GSF Central Team with local facilitation and adaptations.
- Use of online After Death Analysis (ADA) for audit and benchmarking, measuring key factors such as hospital admission rates and length of stay.
- Focusing on communication, pre-planning, teamworking and support for families.

Was the programme successful?

The GSFCH programme differed from previous initiatives directed at improving end-of-life care in nursing homes in the scale of implementation and indicated the feasibility of such an approach and the resources needed. The importance of a senior member of staff taking ownership and responsibility for implementation has been identified in other programmes and was confirmed in this evaluation when the absence of a co-ordinator was found to be a factor in homes that were unable to complete the programme.[24]

While the findings are encouraging, there was no control group and we cannot be certain that the changes seen are solely the result of the GSFCH programme. Follow-up of homes that have just completed phase three (June 2007) will help to indicate whether the changes seen following phase two reported here can be attributed to the GSFCH programme, are the result of other changes in the care homes context, or are due to a combination of factors.

What we should do now

Further research is needed in this important area. This evaluation included a small number of residents and there is a growing body of work documenting older people's reflections on living and dying in a care home.[5,7,30]

Other drivers to improve end-of-life care can be identified. Regulatory frameworks aim to ensure minimum standards in care homes and some of the improvements in this care sector can be attributed to a desire to improve end-of-life care. However, the increasing size and competitiveness of this market for providers may also act to improve standards, alongside responding to the wishes of older people and their families.[31]

The GSFCH programme has since developed further into a three-stage quality-assured programme, with 600 homes participating, and now with an emerging formalised accreditation process. Unlike GSF in primary care, this very structured programme is run solely by the GSF Central Team, with local adaptations.

Provision of timely, quality end-of-life care is important for residents, their families and staff and should not be left to chance. The GSFCH offers one example of the process of implementing change in this area on the required scale.

For more details, contact the GSF Central Team via www.goldstandardsframework.nhs.uk or K.Thomas2@bham.ac.uk

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