

ST COLUMBA'S HOSPICE BRIDGES INITIATIVE PROJECT

PHASE III – Executive Summary



Developing quality end of life care in eight independent nursing homes through the implementation of an integrated care pathway for the last days of life

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Executive Summary

In 1999, the Board of Governors at St Columba's Hospice provided funds for a 5-year action research project to bridge the gap between the Hospice and local nursing homes (Bridges Initiative 1999-2004). This came about as a result of encouragement by the Scottish Executive to disseminate palliative care knowledge, gained by specialist palliative care staff within the Hospice Movement, to those in generalist settings. It was a project with a defined life-span; any development as a result of the project needed to be independent of any hospice support once the project had finished. The project had three distinct phases:

- Phase 1: A survey of independent nursing homes in Lothian (Hockley 2004a)
- Phase 2: An action research study in two nursing homes identifying ways to improve practice in end of life care (Hockley 2004b)
- Phase 3: The implementation of an 'integrated care pathway (ICP) for the last days of life' in eight nursing homes across Lothian

It is the final phase (Phase 3: October 2003 – September 2004) which is the subject of this report but it is inevitably linked with the previous two phases.

Background

As a result of the Community Care Act (1990), care homes have now become the major provider of long-term care for older people. One in five older people in the UK dies in a care home (Teno 2003). However, research has shown that care homes have become isolated from innovations in palliative care practice (Sidell et al. 1997). Research also indicates that educational initiatives to promote palliative care for care home staff may not lead to subsequent change in practice because of organisational and cultural barriers within the care home (Froggatt 2000). There is an increasing pressure to implement evidence-based guidelines in practice so that care can continuously improve. Owing to the changing culture of nursing homes, palliative care is an important area for development.

Aim of the Study

The aim of this study was to evaluate the implementation of a previously adapted version of the Liverpool Care Pathway for the Dying Patient (Ellershaw & Wilkinson 2003) known locally as the integrated care pathway for the last days of life (ICP) as a way of developing quality end of life care in eight independent nursing homes across Lothian. The objectives of the study were as follows:

- To assess current practice in relation to end of life care in each of the nursing homes;
- To examine the processes involved in implementing the ICP documentation;
- To examine the staff and relatives' perspectives on the value of the ICP document during and following its implementation in each nursing home;
- To evaluate any change in current practice in end of life care, following the implementation of the ICP documentation;
- To explore with staff the impact of educative and facilitative support provided throughout the implementation of the change.

Methods

The principles of action research underpinned the study, whereby the research emphasis was research 'with' and 'for' people rather than 'on' people (Reason 1988). It was important that those taking part took ownership of the study in order for sustainable change to take place. The democratic and participatory principles that underpin action research guided the research design.

Three nurses (a clinical nurse specialist [CNS] in palliative care with research experience, a nurse experienced in action learning and action research, and a nurse evaluator with palliative care experience) made up the 'core' research team alongside key champions in each nursing home as 'insiders' / co-researchers. A significant number of key champions had undergone a validated 'palliative care for the elderly' course.

A variety of methods of enquiry were used to explore how end of life care was managed in the eight nursing homes prior to the implementation. The methods included:

- Documentary analysis;
- Field notes – taken throughout the study by the evaluator and CNS/researcher;
- Participant observation;
- Interviews with relatives, and nursing home managers, group interviews with trained staff, care assistants and some GPs; and
- Culture and Organisation of Care questionnaire (Bate 1994)

Facilitation of the implementation of the ICP included:

- The use of action learning sets for key champions;
- Education sessions on the use of the ICP documentation to key champions and subsequently to all nursing home staff within their own nursing homes;
- Collaborative learning groups following a death in the nursing home for all staff; and,
- Regular clinical support from the CNS/researcher.

A multi-method approach was used to evaluate the impact of the implementation of the ICP on end of life care. This included:

- Final group discussion in each nursing home;
- Interviews with key champions;
- Questionnaire to nurse managers; and
- Questionnaire to all care home staff.

Key Findings:

Barriers to the implementation of the ICP document and the development of quality end of life care at the commencement of the study were highlighted under three main headings:

- *organisational barriers*: time constraints and staffing instability; lack of a learning culture leading to a lack of motivation; and support difficulties both within and outside the nursing home with a lack of a GP 'relationship' in some nursing homes.
- *cultural barriers around death and dying*: 'striving to keep alive'; 'closed' discussion around death and dying; and, difficulties around end of life decision making;
- *clinical barriers*: 'imminent dying' not recognized; and, a lack of knowledge of palliative care drugs.

The design of the study was such that it was able to overcome the cultural and clinical barriers in a majority of the nursing homes. However, the organizational barriers were more difficult to address within the timescale (one year) and the scope of the study.

One overarching pattern and five themes emerged from the qualitative analysis. The overarching pattern was that dying had become 'less peripheral' to nursing home care as a result of there being:

- a greater 'openness' around death and dying
- nurses/carers taking responsibility to recognise and mark the dying process
- better teamwork in end of life care and valuing of the care assistants role
- 'critical thinking' around palliative care knowledge to influence practice
- more meaningful communication with dying residents/relatives

There was a greater emphasis on the naturalness of dying in the very old and the holistic care of residents and families. Spiritual care was least understood.

Analysis of the quantitative data showed that 'prn' medication was used for 93% of residents who died following the introduction of the ICP documentation compared to 23% prior to the implementation. Antibiotics in the last days of life were used for 5% of residents where prior to the study 33% of residents were still prescribed antibiotics at the time of death. The prescribing of antibiotics tends to give a pro-life message thus giving a mixed message regarding 'dying'.

Where there was already a working relationship between the nursing home and a local GP practice, and in particular where the GP practice was providing the majority of medical cover to residents in the nursing home, implementing the ICP and therefore its influence on quality end of life care was easier to achieve.

Conclusion

This study confirms the usefulness of an integrated care pathway for the last days of life as an important tool in facilitating evidence-based quality end of life care in nursing homes. In the nursing homes studied, dying became less peripheral to the care culture. Use of the ICP documentation encouraged a greater openness around death and dying, with nurses and carers being more prepared to take responsibility for recognising and marking the dying process. The process encouraged a greater sense of teamwork, valuing the care assistants' role, and increased critical thinking around end of life care. Dying was

accepted as a more 'natural event' at the end of life and nurses were less fearful of engaging in conversations about dying amongst themselves, with families and on occasions, with residents.

Appointing 'key champions' within each nursing home was an important facilitative aspect of the study. Where a key champion had had previous exposure to a validated course in palliative care, and where there was a 'working relationship' with one key GP practice, there was an increased likelihood of the ICP tool becoming embedded in the day to day practice and for changes in end of life care therefore being sustained. It is important that palliative care education and practice development go 'hand in hand' in order for quality end of life care in nursing homes to be achieved.

Key Recommendations (see main report for fuller explanation of recommendations):

- 1. Recommendations around end of life care in nursing homes**
 - Systems in place to ensure that palliative care plays a greater role in the induction/mentoring of nursing home staff.
 - A strategic approach to encourage nursing homes (NHs) to form 'working relationships' with one local GP practice.
 - An emphasis on patient-focused/person-centred approach to care in NHs.
 - A process to be undertaken to encourage a greater learning culture in NHs.
 - A greater awareness of the knowledge of drugs available to control symptoms at the end of life.
 - A re-examination of the legislation around drugs for end of life care in NHs.
 - A strategic approach to connect independent NHs to innovative palliative care practice through a support team to promote practice development and research.
 - An evaluation of the 'for profit' image of independent NHs.

- 2. Recommendations when using an integrated care pathway for the last days of life document as a way of developing end of life care.**
 - A practice development framework with the appointment of key champions within each NH is recommended.
 - The facilitation process used to support staff in the development of practice must challenge staff assumptions and beliefs
 - The ICP document is a useful tool for auditing quality end of life care in NHs as a basis for practice development.

- 3. Recommendations for further research in end of life care in nursing homes**
 - In order to capitalise on this study, further projects could be undertaken whereby NHs that have embedded the ICP in their practice would develop smaller projects around end of life care which would be formally evaluated.
 - Research on the holistic care with particular attention to the spiritual/pastoral needs of residents at the end of life is advocated. Pastoral work in NHs is relatively unresearched.
 - This study focused attention on 'before death' and 'during death' but research specifically on 'after death' in NHs is suggested; for example, examining the grieving needs of other residents, and relatives.
 - More in-depth research is required to address the differences in the dying trajectory of older people compared with the pattern of death observed for example in mid-life cancer. Assessments of such differences are at present very subjective.
 - The role of a nurse practitioner (gerontological palliative care) within the NH structure as a means of enhancing the clinical role of nursing in this setting requires investigation.
 - Researchers in this study were aware of the stress of working in NHs and believe an important area of research would be to examine the role of leadership particularly when transformational leadership might be appropriate to this setting.

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