

ST COLUMBA'S HOSPICE BRIDGES INITIATIVE PROJECT

PHASE II



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:

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| 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 to form 'working relationships' with one local GP practice.
- An emphasis on patient-focused/person-centred approach to care in nursing homes.
- A process to be undertaken to encourage a greater learning culture in nursing homes.
- 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 nursing homes.
- A strategic approach to connect independent nursing homes to innovative palliative care practice through a support team to promote practice development and research.
- An evaluation of the 'for profit' image of independent nursing homes.

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 nursing home is recommended.
- Facilitation 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 nursing homes 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 nursing homes 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 nursing homes is relatively unresearched.
- This study focused attention on 'before death' and 'during death' but research specifically on 'after death' in nursing homes 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 nursing home 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 nursing homes 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.



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

Chapter 1

Introduction and brief review of end-of-life care in nursing homes

The impetus to carry out this study was a direct result of two previous phases of a larger project (Bridges Initiative 1999-2004) undertaken to bridge the perceived gap between hospice care and care given at the end-of-life in nursing homes¹. The initial phase of this larger project was a survey of independent nursing homes across Lothian (Hockley 2004a). This formed baseline data for a three-year action research study in two volunteering nursing homes (Hockley 2004b). It was during this part of the project that a nurse (with previous palliative care experience) from one of the nursing homes suggested developing a tool that would help guide them in anticipating care during the last days of a resident's life. Ellershaw et al. (1997), and Ellershaw & Coackley (2002) had recently published work on the Liverpool Integrated Care Pathway (LCP) for the Dying Patient. A small group (consisting of the nurse manager, nurses, care assistant, GP and representation of the Care Commission) was convened in the nursing home to consider the LCP as a suitable document. An adapted version of the LCP was developed and piloted by staff in the nursing home and came to be known as the 'integrated care pathway (ICP) for the last days of life' document.

Following a successful pilot of the ICP document, where nurses felt it was an important guide to the effective control of distressing symptoms, and where the tool particularly highlighted the lack of psycho-social/spiritual care for residents and their families at the end-of-life, a decision was made to use the tool as a way of 'widening' the development of quality end-of-life practice in other volunteering nursing homes across Lothian. This report presents that study – a study to develop end-of-life practice through the implementation of an 'integrated care pathway (ICP) for the last days of life' document in eight independent nursing homes across Lothian.

The study began in September 2003 and ran for a full year. The 'core' research team was made up of three nurse researchers:

- two project managers – both experienced nurses, one experienced in specialist palliative care who worked full-time on the study; and the other experienced in action research and 'action learning' who worked 3 days a month
- one evaluator – experienced in palliative care nursing and evaluation research

Action research methodology continued to underpin the research approach of this final phase. An evaluation of the process of change was an integral part of the study. Two key champions from each nursing home played their role as co-researchers. Documentary analysis, field notes, participant observation, interviews (relative interviews, group discussions, nurse manager's interviews) and a culture/organisation questionnaire were used to examine practice prior to the implementation of the ICP document. The impact of the study was evaluated through interviews (key champions, group discussions in each nursing home), a questionnaire to nurse managers and a clinical audit questionnaire to all nursing home staff.

¹As a result of the Regulation of Care (Scotland) Act 2001 any legal differences between nursing and residential homes no longer exists. All homes became 'care homes'. However, in essence, care homes 'with nursing' inevitably shoulder a greater burden of more dependent residents with more complex medical problems. They also shoulder a higher death rate than care home (residential). For the purpose of this study and the ease to the reader, we use the term nursing homes instead of care homes (nursing) as this in reality was what people referred to them as in the study. When referring to both types the term care home is used.

1.1 PALLIATIVE CARE AND CARE HOMES

The Hospice Movement that began in the mid-1960s has been very successful in promoting specialist palliative and end-of-life care for cancer patients. However, it is only since the late 1990s that there has been a greater emphasis on applying some of the knowledge developed within specialist palliative care to other diseases and in other settings (NCHSPCS 1997).

The image of nursing homes as places where older people seek companionship in the latter years of life has changed. Instead, nursing homes have increasingly become places where frail, older people in need of 24-hour nursing are cared for. One in five of the UK population over the age of 65 years will end their life in a care home (Teno 2003). A similar figure of 17% is recorded in Scotland (SCCS, 2001; ISD 2001). This increase has occurred largely as a result of The NHS and Community Care Act 1990 against a backdrop of an increasing older population and the closure of long-stay geriatric wards.

Deaths in independent nursing homes in Lothian during the ten years from 1989-1999 increased nearly fourfold (personal communication, LHB 2000). In 2001 there were 1,076 deaths in nursing homes across Lothian, accounting for nearly a third of the total number of the 3,700 beds (Care Commission, personal communication). A majority of residents in nursing homes die within two years of admission from multiple medical pathologies including dementia, with less than ten per cent of residents dying from a diagnosed cancer (Sidell et al. 1997; Hockley 2004a). However, there is a growing body of research not only describing low morale, poor retention and recruitment of staff in nursing homes (Redfern et al. 2002b) but also highlighting poor symptom control and the subsequent suffering at the end-of-life (Hall et al. 2002; Ferrell 1995).

With the greater number of care homes being established in the community, a greater burden has fallen on local GPs to give medical cover. Very little thought appears to have gone into how frail older people, particularly those requiring 24-hour nursing, receive appropriate medical care (Jacobs 2003). The implications that this might have, not only for residents but the care environment, are a concern.

Research in the UK shows that care homes can become isolated from recent innovations especially those regarding pain control and palliative care (Gibbs 1995; Sidell et al. 1997; Katz & Peace 2003). Many hospice/specialist palliative care units run courses for care home staff. However, when evaluating a course funded by Macmillan Cancer Relief for nurses and care staff from care homes in England, Froggatt (2000) found that, although individuals had really appreciated the course, there was difficulty changing the institutional practices of nursing homes involved. Facilitating practice development using evidence-based guidelines (Kitson et al 1998; Rycroft-Malone et al 2004) may be one way in which to develop end-of-life care in nursing homes especially when research not only reports sub-optimal care, but also where education on its own is not managing to change practice. An integrated care pathway (ICP) was considered to be a useful tool to promote evidence-based practice in the last days of life.

All care pathways detail the essential steps of care in a specific clinical problem and can be used to introduce clinical guidelines and systematic continuing audit into clinical practice (Campbell et al 1998). Ellershaw et al.'s (1997; Ellershaw & Coackley 2002) pioneering work in the UK on the Liverpool Care Pathway for the Dying (LCP) is framed around evidence of quality end-of-life care taken from the experience of specialist palliative care. The tool is founded on the WHO's definition of palliative care:

"Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual..." (WHO 2002)

The LCP has a goal orientated focus around end-of-life care. It details a timeframe of assessments – an initial assessment followed by 4 hourly and 12 hourly assessments – that guide the holistic care for a person in the last days of life. Any variances from the goals of planned care are noted and acted upon. This is a key feature of the dynamic nature of any care pathway to promote individualized care.

The LCP was used as a template to develop the ‘integrated care pathway (ICP) for the last days of life’ specifically for a nursing home in Phase II of the larger project. It was this document that was used at the beginning of Phase III. Some work into the effectiveness of an integrated care pathway for the last days of life has been done (Jack et al. 2003). However, no such work has been done within the care home sector in the UK. To see if an integrated care pathway for the last days of life could help develop and sustain quality end-of-life care within the nursing home sector was the basis for this study and is the focus of the following chapters.

Chapter 2

Methods of the Study

This chapter discusses the rationale for the methodology and describes the methods used to explore the overall aim of the study which was:

To evaluate the implementation of an 'integrated care pathway (ICP) for the last days of life' document in eight independent nursing homes across Lothian.

In addition to this, the study aimed to bring about change in practice around end-of-life care and to evaluate the processes and outcomes of this change.

2.1 RESEARCH OBJECTIVES

The objectives of the research 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 of end-of-life care following the implementation of the ICP documentation; and
- To explore with staff the impact of educative and facilitative support provided throughout the implementation of the change.

Action research (AR) was the methodology that was chosen to carry out this work since it is conducted with and for people rather than on people (Reason 1988). This emphasis on participation was important since we were interested in developing practice in relation to quality end-of-life care that would lead to sustainable change. Sustainable change has a much better chance of success if people have ownership of the study (Balfour & Clarke 2001). In addition it was important in this study to develop new knowledge, in order to inform practice about end-of-life care in care homes. It was anticipated that this approach would enable us to continue to reshape the theory inherent in the integrated care pathway, to reflect a theory that is perhaps more relevant to practitioners working in care homes. Indeed Meyer (1999) and Rolfe (1998) argue that the knowledge that is generated from action research is often a different kind of knowledge, more meaningful to practice.

Evidence from other action research studies, and previous work by the research team, highlighted the importance of having adequate time to feed ongoing findings into the process of change so that future actions can be further planned, implemented and evaluated (Hart & Bond 1995; Meyer 1999). These actions are often referred to in the literature as action reflection spirals (McNiff 2002). Given the short duration of this study (12 months), the extent to which future actions could be implemented and evaluated was limited. However, what the study findings do provide are important actions that need to be considered in the future implementation of the ICP documentation.

Hart and Bond (1995) present a typology to classify different types of action research. They identify four basic types: experimental, organisational, professionalizing, and empowering. It was difficult however to select a type that fitted this study since the study had characteristics that could fit different aspects of all types. For example, in relation to the change intervention, the study met the criteria for the experimental approach in that the intervention was predetermined by the research team. However, in

relation to the educative base employed in the study, it fitted the professionalizing, organisational and empowerment approaches, where the aim was to enhance professional control through increased end-of-life knowledge, and the individual's ability to control the work situation alongside empowering oppressed groups – in this instance care home staff. The extent to which we achieved a classical empowerment approach to this study was influenced by the workplace cultures in which the study took place. Indeed Somekh (1994) argues that occupational cultures can affect action research methodology, and suggests that action research needs to be grounded in the values and discourse of the individual group rather than rigidly adhering to a particular methodological perspective.

The democratic and participatory principles that underpin AR guided us in the research design. The researchers continually fed back findings from the study to participants who in turn had the opportunity to comment on the data collected. The key champions appointed as 'insiders' within each nursing home helped to influence the implementation of the study from within the nursing homes.

Literature on theory of change, practice development and promotion of evidence based practice were reviewed to identify aspects that are important to the process of change and the sustainability of projects over time. These aspects needed to be considered in the design of this study and include:

- Organisational commitment
- Strength and relevance of the evidence to practitioners who have to make the changes
- Clear understanding of the culture of the organisation into which the change is to be implemented
- Importance of facilitation to support those bringing about change
- Identification of key individuals to act as lead change agents
- Importance of creating an environment where peers can share and develop new knowledge
- Importance of challenging 'espoused' theories and 'theories in use' if change is to be effective

2.1.1 Organisational commitment

Organisational commitment to an initiative is frequently cited as important in the change process (Stocking 1992; Redfern et al 2000a). Securing the support of the managers in this study was considered key to its success. Organisational commitment within the nursing homes needed to include nurse managers and, where appropriate, owners. Securing this commitment was challenging since the extent to which owners were involved in strategic decisions about care varied, with some owners being very involved and having some background in health and social care, and others devolving this responsibility about decision making around care issues to the nurse manager. Nurse managers were written to in the first instance to invite them to declare an interest in taking part in the study. In addition, they were invited to dissemination events throughout the study and were included as participants in the research process, where their views about the progress of the study were sought at different intervals.

On the whole managers were keen to be involved. However, in one study site the owner had visited the nursing home and had seen returned questionnaires in an envelope on the wall that had asked staff to anonymously comment on the organisational culture within which they worked (see section 2.3.3). The owner was very concerned about this aspect of the study and made a decision to withdraw from the study.

2.1.2 Strength and relevance of the evidence to practitioners who have to make the changes

Williamson (1992) stresses the importance of the strength and relevance of the evidence base in the success of implementation. In relation to the strength of that evidence Kitson et al. (1998) argue that the level of evidence is important to the success of the implementation, and describe different types of evidence ranging from high to low. In evaluating the evidence base, one needs to consider the rigour of the research process that has produced the evidence, professional consensus and patient consensus. The relevance of the evidence to professionals is as crucial as the evidence itself (Nutting et al. 1994).

In relation to the evidence that was to be implemented in this study, it was the integrated care pathway for the last days of life. Integrated care pathways (ICPs) determine locally agreed, multidisciplinary practice that is based on guidelines and evidence, where available, for a specific patient/user group. The ICP document forms all or part of the clinical record, documents the care given around the achievement of goals and facilitates the evaluation of outcomes for continuous quality improvement (Riley 1998). Ellershaw et al (1997; Ellershaw & Wilkinson 2003) first developed the Liverpool Care Pathway (LCP) for the Dying Patient basing it around a review of the literature, patient documentation and multidisciplinary discussion. Key outcomes/goals in quality palliative care form the framework of the documentation around:

- identifying patients who are dying and making a 'diagnosis' of dying
- an initial holistic assessment and reporting of any variance from the stated goals
- on-going 4 hourly assessment 'goals' observing symptom control and the giving of physical care and reporting of any variance
- on-going 12 hourly assessment 'goals' around the psycho-social/spiritual care of residents and family and reporting of any variance
- care after a death.

The World Health Organization definition of palliative care² underpins the pathway in its holistic approach to care. The relevance of the LCP to nurses working in a number of independent nursing homes had not been evaluated. It was important therefore that the evidence in this study, the ICP documentation, was used critically rather than uncritically. By this we mean that we had to adopt a methodological approach that was flexible and that allowed the evidence to be modified as the study progressed.

2.1.3 Clear understanding of the context into which the change is to be implemented

Successful implementation of change has been shown to require a clear understanding of the culture of the organization into which the change is to be implemented (Handy 1994).

Key factors that shaped the nursing home context in which this study was carried out included:

- Variable learning culture and professional development strategies for staff
- Recent changes to the monitoring and quality of care homes through the Care Commission processes with subsequent impact on staff
- Changes in skill mix with the employment of many overseas care assistants presenting different challenges to nursing home staff

² "Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual..." (WHO 2002)

- High staff turnover and low employee skill base
- High dependency level physical and/or mental frailty in the residents in nursing homes
- Nursing homes increasingly being the place where older people die

An understanding of these key factors enabled the research team to shape the methodology of the study so that it was more relevant and meaningful to the participants. In addition, presenting a rich description of the context (see Chapter 3) in which the study took place will enable readers to better judge the relevance of the findings to their own settings.

2.1.4 Importance of facilitation to support those bringing about change

Kitson et al. (1998) have developed a multidimensional model for understanding the process of implementing evidence into practice. The model considers the relationship between the nature of evidence, the context in which the change is taking place and the facilitation mechanisms. They argue that facilitation is key to success in bringing about change. Facilitation as a key factor is rarely emphasized in other literature relating to research utilization.

The facilitation in this study took a three pronged approach:

- i Action learning
- ii Collaborative learning groups following a death
- iii Clinical palliative care support

Action Learning (AL) is a process of learning and reflection that happens with the support of a group or set of colleagues working with real problems with the intention of getting things done. The participants in the group or set each take forward an important issue with the support of other members in the set. The process helps people to take an active stance toward life and helps overcome the tendency to be passive towards the pressure of life and work (McGill & Beaty 2001). The key champions were invited to take part in a series of six action learning sets that ran each month throughout the course of the study. In total three sets were formed, with each set comprising key champions from two different nursing homes. This enabled the key champions to develop relationships and share experiences with others outside their own immediate care setting. Each set meeting was held at the hospice and lasted for approximately three hours. On average this enabled two or three individuals to present their issue at each meeting. Detailed notes were written up after each set meeting and these were fed back to set members prior to the next session.

Collaborative learning groups (CLGs) held monthly in each nursing home provided the opportunity for nursing home staff and researchers to come together to learn about aspects of end-of-life care, the importance of team communication, the necessary support of colleagues following the death of a resident and the opportunity to examine the used ICP documentation. Because a large proportion of people working in care homes are untrained (though not unskilled) care assistants with little experience of a learning culture, a more formal model of reflection was thought inappropriate in conjunction with the limited time available for each session. It was also important to be able to give essential teaching on aspects of care as and when the occasion arose within the group. The groups were organised so that:

- Groups were held at each nursing home every month for 6 months of the study
- Each session lasted on average 45 minutes
- Key champions were encouraged to organise the groups and were expected to attend
- Staff involved in caring for the resident who had died were specifically encouraged to attend
- If no death had occurred during the previous month then the time was used to explore an aspect of palliative care that staff requested

In some nursing homes the CLGs did not commence straight away because of difficulties with staffing which meant that not all the nursing homes had the same number of sessions. The CLGs are discussed further in section 2.3.4 and Chapter 4:2.

Clinical palliative care support was offered through the experience of the CNS/researcher as a clinical nurse specialist in palliative care. Within the context of a specialist palliative care team, experienced nurse specialists have been shown to improve knowledge and change attitudes of clinical staff when the contact has been for 6 months or longer (Farrer et al. 2004).

Nurses from the nursing homes were able to contact the nurse specialist on clinical issues around palliative care for the duration of the study, if the appropriate GP had been informed. Nurses would seek advice either via the telephone or face to face separate to or following a collaborative learning group. Issues were 'worked through' together with the nurse specialist encouraging critical thinking about any given situation, rather than just the giving of advice.

2.1.5 Identification of key individuals to act as lead change agents

There is evidence to suggest that approaches which give participants a feeling of power within the process of change are considered important and effective (Eldridge & South 1998). In this study this involved identifying key champions in each of the nursing homes who would take responsibility for implementing the ICP. In addition to this, they had a key role in promoting the study amongst colleagues in their workplace. In this way the key champions had an important role in shaping the success of the study. Their ownership of the study would influence the sustainability of practice related to end-of-life care in the future when the study ended.

2.1.6 Importance of creating an environment where peers can share and develop new knowledge

Creating an environment where information is shared and new learning developed can be linked to the concept of a 'community of practice'. The concept 'community of practice' was developed to illuminate that learning is a social experience (Lave & Wenger 1991). It purports that humans learn best when in relationship with others who share a common practice, and that we self-organise as communities with those who have skills and knowledge that are important to us. In this way we created a community of practice that included researchers and practitioners, all of whom wanted to pursue the development of knowledge in relation to end-of-life care. Key champions had the opportunity to meet, on several occasions throughout the study, other key champions in nursing homes to discuss common themes and develop new knowledge.

2.1.7 The importance of challenging espoused theories and theories in use if change is to be effective

People are not always consciously aware when their espoused theories lack congruence with their theories in practice. If change is to be effective the methodology needs to incorporate ways of challenging any lack of congruence. Indeed Manley (2000) identifies two processes important to facilitating cultural change within health care organisations: the use of values clarification with staff to guide ways of working, future directions and the creation of a common vision; and, highlighting contradictions between espoused values and values in use. A values clarification exercise (see 2.3.3 below) and action learning were the processes used in this study to challenge espoused theories and theories in use.

2.2 ROLE OF MEMBERS OF THE 'CORE' RESEARCH TEAM

2.2.1 Project Managers

There were two project managers who had overall responsibility for the quality of the study. The project managers had different professional backgrounds and different levels of experience. One had extensive experience in specialist palliative care (CNS/researcher) and had been responsible for carrying out a previous action research study that looked at developing knowledge of end-of-life care in nursing homes (Hockley 2004b).

The other had a senior position in academia and had extensive experience of participatory research and of working in older people settings. In addition she had played a key role in the supervision of the previous action research study.

2.2.2 Evaluator

The evaluator employed on this study had a six year background in hospice nursing and some previous experience in research for completion of a Masters degree.

2.3 DESIGN OF THE STUDY

The design of the study is best described as following a series of tracks. Several of these tracks occurred simultaneously, but for the purposes of describing them in this report they are represented in sequential order as a list below.

2.3.1 Track 1 – Recruitment

Action research, because of its participatory and democratic nature, does depend on the research team being able to develop good working relationships with participants. A decision to use action research as a methodology meant that we had to consider key factors that would enhance the chances of us being able to establish these relationships relatively quickly. Factors that were considered included Nolan and Grant's (1993:307) criteria for successful implementation of action research namely, that there is 'a shared and explicit set of values acting as a guide for practice; a recognition that a problem area exists; a common understanding of the problem; a perceived need for change; the situation is seen as amenable to change; a focus on involvement and team building. In addition to these requirements, it was important to carry out work in an organisation that is open to learning and that values critical dialogue about practice'. Given these considerations and the short timescale of this study, it was important that the nursing homes included in this study met some if not all of these requirements. In order to establish this, a preliminary letter was sent to 72 independent nursing homes throughout Lothian inviting them to declare an interest in participating in the study. Eleven nursing homes responded; out of these eleven, four nursing home managers had already given the opportunity for one of their nurses to attend an NES (NHS Education for Scotland) validated course in palliative care (St Columba's Hospice/QMUC, Edinburgh).

A member of the study team visited each of the nursing homes to see if they met the criteria and to assess their readiness to take part. The criteria included: a degree of stability in staffing, a commitment from management, a recognition that a problem exists and a willingness to examine current practice and implement an ICP, and, where possible, an existing relationship with one GP practice giving medical cover for a majority of the residents. Selection of nursing homes was based on their ability to meet these criteria and the location of the nursing home. The intention was not to limit recruitment of nursing homes to the City of Edinburgh. Following the visits and after further discussion eight nursing homes decided to take part.

After selecting the eight nursing homes³ the managers were asked to identify two nurses from their home who would act as 'key champions' for the study. It was important that these nurses were in a position to influence change and had a commitment to developing palliative care within the home. These key champions would act as core participants and would be involved at all stages of the study. Other participants in the study included all care staff in the home, the managers, and GPs.

2.3.2 Track 2 – Developing relationships with participants

Several initiatives were put in place to ensure that there were opportunities to develop relationships with the participants. These included two social events and regular meetings (monthly) with the key champion/s and nurse manager in each home. These meetings were primarily designed to update participants on progress. The monthly collaborative learning groups and the action learning sets helped to develop relationships with those 'at the coalface'.

2.3.3 Track 3 – Examining what was currently going on in practice

A variety of methods of enquiry were used to explore the research question of what is currently happening in practice in relation to end-of-life care and to explore contextual issues in each care home. Both qualitative and quantitative data collection methods were used and included:

Documentary analysis:

Case notes and prescription charts of the last five residents to have died in the nursing homes were examined (NH.B & NH.C were being counted as one at this point in the study). Five residents out of the 35 case notes collected had died suddenly and examination was made of the remaining 30 documents. The LCP base review audit chart (Appendix 1) which had already been developed by the research team based in Liverpool (Ellershaw & Wilkinson 2003) was used to analyse these documents. Items for scrutiny included: comfort measures which included the appropriate prescribing of drugs for end-of-life care, psychological/insight issues of resident and family, religious needs, communication with family and members of the primary care team, ongoing assessment on symptoms, and care after the death.

Field Notes

From the outset of the study the evaluator and CNS/researcher kept field-notes which served to keep a record of day to day events and reflections about the study. These were used alongside other sources of data to provide a more comprehensive decision trail in the study.

Participant Observation

The evaluator spent one day in each nursing home observing care practices. Her observations where possible were focused around care of the dying. In order to give some structure to the observation the 'palliative care approach'⁴ and Singer's five domains of quality end-of-life care guided the observation (Singer et al. 1999). Opportunities to observe care for the dying had to be taken as they arose. If there was a resident dying in the nursing home, or the staff thought the person was dying, then some time was spent helping to care for this person, talking with staff about their thoughts, and looking at their nursing notes and medication charts. The evaluator had the

³ It has already been mentioned that one nursing home withdrew from the study. However, at recruitment what was thought to be one nursing home was found to be split in two locations of the city – this nursing home then became two nursing homes which kept recruitment at eight nursing homes.

⁴ The palliative care approach requires attention to: quality of life which includes good symptom control; whole-person approach taking into account the person's past life experience and current situation; care which encompasses both the person who is dying and those that matter to the person; respect for patient autonomy and choice; emphasis on open and sensitive communication which extends to patients, informal carers and professional colleagues (NCHSPCS & SPA 2000: 14)

opportunity to be present when a GP came in to see one resident who was very unwell and 'diagnosed as dying'. This gave an opportunity to observe the discussion between the nurse and the doctor and how they assessed the resident's symptoms and decided what medication to use. There was some opportunity to see how they communicated with the family.

In situations where no one was dying, the opportunity was taken to help out with care, including feeding and toileting, which was useful for gaining an insight into the general culture of the home. This included: how care was organised, how the team functioned, and the roles of different members of the team. This was felt to be important contextual information in terms of the factors which may impact on the ability of each home to implement a change such as using the ICP documentation. There were opportunities to talk informally with staff about their experience of caring for the dying and the 'good deaths' and 'bad deaths' they had experienced. The staff were very willing to talk about this and usually spoke about these situations without much prompting.

Another strand of the observation was the degree of openness in communicating about dying between staff, staff and residents, and staff and families. This information was picked up in handovers from nursing notes and informal conversations.

The evaluator took brief notes during each visit and at the end of each visit wrote more detailed notes, initial thoughts and some preliminary themes.

Interviews

Relative interviews: Relatives of seven residents who had died prior to implementation of the ICP documentation were invited to share their experiences of the last days of life of their family member in order to gain an understanding of what was currently happening. All the relatives interviewed were approached initially by a member of the nursing home staff. If they were interested to take part in the study, they were then contacted by telephone by the evaluator and sent an information sheet (Appendix 2). A consent form (Appendix 3) was signed by the relative at the beginning of the interview. Each semi-structured interview (Appendix 4) was conducted in the relative's own home and lasted no more than 40 minutes and was tape recorded. Following the implementation of the ICP a further two relatives were interviewed. However, because of the short time-span of the study, it was felt that the bereavement time was too short for any further post-ICP relatives to be interviewed. All relatives interviewed were those of residents that staff perceived to have had a good death. Some unsuccessful attempts were made to interview relatives of residents who were perceived to have had bad deaths.

Group discussions using the 'values clarification' exercise: Group discussions were carried out in each home with a range of nursing home staff to elicit their values and beliefs about what represents good end-of-life care, and the extent to which their nursing home was able to deliver this. It focused also on their perceptions of what factors hindered and facilitated this process. The evaluator met with teams of nursing staff and care assistants to explore this in a group discussion using the framework of a 'values clarification' exercise (see Appendix 5). This was then collated and fed back to staff. The benefit of using this approach meant that we could establish a common vision about end-of-life care in the home. In addition it provided us with a framework from which to evaluate practice towards the end of the study (see 2.3.6). The values clarification exercise also provided a useful way for staff to indicate areas that they felt were important to end-of-life care but in which they needed to develop further expertise.

Manager interviews: The nurse manager in each nursing home (n=6⁵) was interviewed at the start of the study (Appendix 6). This was to ascertain how they felt about end-of-life care in nursing homes and how they might want to see things change. It also drew attention to the study and their role in it.

Culture and Organisation Questionnaire: The culture within each nursing home was assessed using the Culture and Organisation Questionnaire developed by Bate (1994) (Appendix 7). This questionnaire asks people to rate on a numerical rating scale of 1 – 5 how they feel about the organisational culture in which they work and includes questions about how decisions are made, and how individuals in the team work together. It was felt that this was an important assessment in order to establish how staff view the cultural and organisational context in which they work and how this in turn might impact on the success of the change. It had been the intention to repeat this questionnaire at the end of the study however, the return rate of the questionnaire was extremely low, and a decision was made not to repeat this but to use the results to confirm themes and aspects of observation that were being made in the study. Results of the questionnaire were fed back to each nurse manager. The poor response rate to this questionnaire does raise questions about whether it is an appropriate method for data collection in this context.

2.3.4 Track 4 – Introducing the educational and facilitative programme

Action learning set meetings were arranged with each key champion. Key champions from two or three nursing homes made up one of three sets that were held monthly for six months. Each set lasted three hours. Meetings were held at the hospice so that the sessions were not interrupted. Nursing groups have been found to be more willing to participate when an event is held away from the practice setting (Miller et al. 1998).

Education sessions on the use of the ICP documentation were held for the key champions from each nursing home in three 3-hour periods at the hospice during the first month of the study by the CNS/researcher. A scenario on 'end-of-life care' (Appendix 8) written specifically for Phase II of the larger project was used to practice completing the ICP documentation and address issues around death and dying. All key champions were involved in helping with the training sessions alongside the CNS/researcher. The key champions subsequently arranged training for the rest of the staff in each of the nursing homes.

Some key champions chose to have just one initial training afternoon for nurses, with the key champions taking responsibility themselves for follow-up training of all care staff on a bi-weekly basis. Other key champions chose to do all the training for both nurses and care assistants together with the CNS/researcher in a one and a half hour slot on a rolling basis, using an afternoon/evening in order to make sure all day and night staff attended. In a couple of nursing homes because of staffing instability, further initial training on the use of the ICP documentation was done while the study was on-going.

Collaborative learning groups (CLGs) were initially planned to take place a few days after the death of a resident in the nursing home. However, the unpredictability of the number of deaths changed this as it was realised that nursing homes who had more deaths would receive more visits than a nursing home with fewer deaths. After the first month, monthly CLG's were arranged in advance. Any deaths that occurred in the previous four weeks were reflected on along with the ICP documentation. If a death had not occurred then the time was used to discuss a topic of the key champion/staffs' choice. Some nursing homes, however, delayed starting the CLGs because of difficult staffing issues alongside key champions' leaving.

⁵ NH.B & NH.C were part of the same company as previously stated so only one nurse manager was interviewed. The nurse manager of another nursing home (NH.A) left before interviews began – it was thought inappropriate to interview the nurse 'acting-up' as she was already a key champion.

Each CLG lasted 45 minutes and were held at a time convenient to the nursing home. Mostly this was early afternoon to accommodate both the early and late shift. More often than not, care assistants attending the CLGs following an early shift attended in their own time. Some nursing homes worked with 12-hour shifts. Field notes were taken by the evaluator at each CLG with key champions recording field notes on a couple of occasions.

2.3.5 Track 5 – Implementing the Integrated Care Pathway

The use of action research as a methodology enabled us to constantly analyse the data and feedback issues to staff. It also enabled the research team to reflect on the design of the study and allowed us to improve this in the light of our growing experience.

An introductory meeting in each nursing home to explain the study was held at a time arranged by the key champions during the first month of the study. Two GPs from two different nursing homes responded to the key champions' invitation and attended this session. The sessions lasted around one hour and staff attending were given an information sheet and the opportunity to consent to be part of the study (Appendix 9 & 10). An information sheet, and two A4 envelopes (one for unused consent forms and one for completed forms) were given to the key champions to display in an appropriate place in the nursing home for staff who had not been at the meeting. Consent forms were collected as new staff became aware of the study and chose to actively participate.

Following the introductory meeting and the education sessions around the ICP documentation, the CNS/researcher was informed by a key champion or the nurse manager of the nursing home if there had been a death. A photocopy of the ICP documentation was forwarded to the research team and objectively reviewed in preparation for the collaborative learning group later in the month.

Data were collected during this phase from the action learning sets and the collaborative learning groups. Notes were written up after each of these events and fed back to those who had attended the meetings to check for accuracy. These notes contained a detailed description of what went on, as well as the main themes to emerge from the work the group had carried out and the key action points to take forward. The regular collaboration between the key champions and the research team enabled a stronger relationship to develop which in turn seemed to increase participant's motivation and participation with the study.

2.3.6 Track 6 – Evaluating the impact of the study

A multi method approach was used to collect data in this phase of the study. This included:

- *Final individual nursing home group discussion* (Appendix 11). A 'final evaluation' discussion, which was tape recorded and led by the evaluator, was held in each nursing home to which all staff were invited. Questions were asked regarding what nurses and care assistants had learnt as a result of the study, and the impact it had had on individuals as well as the nursing home itself. Overall difficulties that they had experienced in implementing the ICP documentation were discussed, as well as what they had felt to be most useful about the process.
- *Individual interviews with key champions* (Appendix 12). Key champions in each nursing home (n=12) were interviewed in pairs (where there were two still present). The purpose was to elicit their perceptions regarding the impact of the study on end-of-life care in the nursing home, as well as their reflections on the process of implementing change within the study. Each interview lasted between 30 – 40 minutes and was tape recorded.
- *Questionnaire to managers* (Appendix 13). A questionnaire was sent to nurse managers (n=7) immediately prior to completion of the study to explore the impact of being involved in the project and the sustainability of the practice development around end-of-life care.

- *Questionnaire to all care home staff* (Appendix 14). An audit style questionnaire divided into 51 statements was developed as a result of the 'values clarification' exercise undertaken at the beginning of the study. All care staff were sent the questionnaire and asked to indicate how much the statements were part of the care given at the end-of-life in their nursing home and to what extent the study had influenced this.

2.3.7 Track 7 – Analysis

All tape recorded interviews were transcribed. A more limited transcription was undertaken towards the end of the study where just important quotes relevant to the emerging themes, alongside any contradictory evidence, were extracted. All the data from interviews, field notes, action learning sets, and the collaborative learning groups were stored using the NVivo (QSR 2000) computer software package.

First-level coding of the data in the form of codes/nodes and initial categories/node trees was carried out throughout the study following interviews, field notes, action learning and the collaborative learning sessions, and the data fed back to participants. This was done both manually on the feedback sheets from the action learning sets and the collaborative learning groups, and then using NVivo software – initially 215 codes/nodes and fourteen categories/node trees were identified. Second-level coding was then carried out whereby the initial codes and categories were explored further to clarify their characteristics and evaluate emerging patterns or themes (Dey 1993). Finally, two of the team explored together the patterns and themes to generate a final interpretation that was then checked out with key champions and nurse managers. Quantitative analysis of the documentary evidence and the audit questionnaire was analysed using basic descriptive statistics such as frequencies, percentages with the help of the Statistical Package for the Social Sciences (SPSS 2001) computer software package.

2.4 ETHICS

Ethical approval had already been granted under the main project (Bridges Initiative 1999-2004: Hockley 2004a/b) which had piloted the adapted version of the Liverpool Care Pathway. The Ethics committee was informed of the development of the final phase and the chairman granted ethical approval for this study.

Informed consent was sought from nursing home managers and staff at the commencement of the study. Meyer (1993) argues that at the outset of an action research study it is not possible for participants to give their fully informed consent, since the specific course that the study intends to take is unknown at this point. In this study the implementation of the ICP documentation was a known aspect to the action research methodology but as Meyer suggests the 'core' researchers worked throughout the study with a broad philosophy of 'ethical practice'. This involved considering each ethical situation as it arose, making judgments based on the premise of maintaining the best interests of the participants at each stage.

Issues of confidentiality and anonymity were paramount throughout the study. Anonymity is always a challenge in studies where, because of an individual's position in an organisation, their quotes may be identifiable. The research team in this study made sure that if they were using quotes where an individual was clearly identifiable in the final write up, the individual was asked whether they were happy for their contribution to be included.

No name of any of the nursing homes is identified in the final report.

In the case of interviewing relatives, the key champion in each nursing home took responsibility to assess the appropriateness of such an interview and make the initial contact. Due to the sensitive nature of the topic, support was available from the CNS/researcher if and when necessary.

Key champions were fed back any data that was generated from the action learning sets for both validation, and for agreement to use this in the final report.

2.4.1 Maintaining rigour

The quality of the evaluation was assured in the following ways:

- *Feedback of emerging findings.* The researchers checked out their evolving analysis with participants during interviews, group discussions and meetings.
- *A range of research methods.* Multiple methods of data collection were used to provide cross comparison and validation of emerging findings.
- *Drawing on a range of expertise.* The research team offered a range of expertise in this study including palliative care, development of care staff, and research methodology. We were thus able to widen our understanding of emergent issues.
- *External Steering Group.* An External Steering Group met at regular intervals to advise the research team and monitor progress of the study. Members of the group included: hospice staff (all disciplines represented including pharmacist), GPs, social worker, nursing home manager.

2.5 SUMMARY

The methodology adopted in this study was complex and had to be necessarily flexible to meet the needs of practitioners who were working in the complex world of nursing home practice. The extent to which we were able to encourage the key champions to play a key role in the data collection was limited due to their perceptions of confidence in relation to this, and the real issue of lack of time. Key champions were, however, keen to respond to feedback from the data, and thus shape emerging themes.

The methodology in this study enabled us to systematically gather data about both the processes involved in implementing and using the ICP document, and the impact this made on the practice of end-of-life care. In addition, it supported individuals in practice to learn from the experience, and to begin to influence policy regarding end-of-life care in the nursing home.

Chapter 3

The Context of Nursing Homes – prior to the intervention

This chapter looks at the context of the nursing homes prior to the commencement of the integrated care pathway (ICP). It describes barriers and facilitating factors relating to the implementation of the ICP documentation being used as a tool to develop end-of-life care.

McCormack et al (2002) detail the importance that the 'context' plays in the initiation of practice development projects. It was therefore important to understand the existing context within each nursing home in order to understand inherent barriers and facilitating factors. As previously highlighted, any practice development initiative in nursing homes is currently taking place against a background of multiple changes. These include changes in the status of nursing homes to care homes, changes in the complexity of needs of the residents, alongside inadequate staffing (Komaromy et al. 2000, Kayser-Jones 2002). These were often the issues presented by key champions at action learning sets, indicating perhaps how difficult it is to focus on practice development when there are other more pressing issues at the forefront of their minds.

The evidence examining the nursing home context prior to using the integrated care pathway is mostly drawn from the participant observation and values clarification exercises held at the beginning of the study in each nursing home, and from field notes gathered throughout the study. A small amount of relevant evidence is also taken from the action learning sets, the final evaluation groups and final interviews with key champions.

3.1 STUDY NURSING HOMES

Eight nursing homes from the independent sector took part in the study. The nursing homes met the criteria (see 2.3.1) as far as possible. Table 3.1 details the differences between the nursing homes in the study – the size, type of ownership etc.

Table 3.1 Nursing Homes taking part in the study

[*NHB & NHC were part of the same company but sited in different parts of the city]

Nursing Home	Number of Beds	Number of units in NH	Ownership	Number of GP practices	Urban/Rural
NH A	60	3	corporate	1 (for majority)	urban
NH B*	28	2	independent	multiple	urban
NH C*	72	3	independent	1 (for 80%)	urban
NH D	47	3	independent	2	rural
NH E	114	4	corporate	1 (for 90%)	urban
NH F	40	3	charity	1	rural
NH G	70	2	corporate	multiple	rural
NH H	54	3	charity	multiple	urban

Jacobs (2003) challenges the lack of efficiency and equality when a number of different GP practices serve a number of different nursing homes. Three of the nursing homes in the study had multiple GP practices attending to the medical needs of residents.

The 'opulence' of some nursing homes suggested that the fees in some of the homes were higher than others. Most nursing homes were divided into separate units averaging 15-20 residents per unit. Despite the project team suggesting that the key champions try to implement changes in one unit only, they all decided to initiate change throughout the home. Some staff had had exposure to palliative care, having either worked in palliative care or completed courses in palliative care. Some also had contact with specialist palliative care services in their own locality.

3.2 BARRIERS

The following is a summary of the main issues which were barriers to implementing the ICP documentation and developing end-of-life care. The three main barriers were organisational, cultural and clinical in nature. Some themes only crystallized at the end of the evaluation when the nursing home staff themselves were able to articulate the changes in the care given to dying residents/families and the subsequent impact on the nursing home culture.

3.2.1 ORGANISATIONAL BARRIERS

Organisational barriers are aspects of the organisational culture that made it difficult for staff to implement the ICP documentation. The barriers also included difficulties around staff attending the monthly collaborative learning groups following a death in the nursing home and key champions attending the action learning sets.

i Time Constraints and Staffing Instability

Staff in the nursing homes were always very busy with the increasing frailty, complex needs and dependency of residents, as well as increased statutory paperwork. At the beginning of the study some nurses saw it all as extra work

"...when they saw the documentation they said you know I've got risk assessments to do, I've got reports to fill in I've got statistics and all that, it's another thing ..."
[NHM. NH.C, interview: para.63].

In most nursing homes there was also pressure on staffing levels, with difficulties experienced not only in recruiting staff but in retaining them. This often made it very difficult for staff to attend training sessions as the work 'on the floor' always had to be covered first.

"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. I would love it to just happen and everybody to be able to attend but that was unrealistic for me to think that but I think we've done OK."
[KC1. NH.C, final interview: para.176]

In addition, agency staff's lack of knowledge about the ICP documentation was an ongoing problem in this study.

"Recruitment is our biggest challenge and it's the same in any nursing home and trying to keep abreast of training and development of staff is very difficult. We have a lot of agency staff coming in for very short periods of time although we do try to contract now with the agencies ..."

[NHM. NH. F, interview. Para.41].

During the year that the study was on-going two nurse managers, one deputy manager, and four key champions alongside a number of care assistants left their jobs at the nursing homes in the study. Care assistants in particular undertake physically exhausting work which is very poorly rewarded financially. In some nursing homes there were inequitable conditions among care staff, with different rates of pay and different annual leave allowances. Care assistants had around four weeks 'annual leave' a year with no public holidays, and no sick pay. It is perhaps not surprising that some staff feel no ownership of practice development initiatives and no loyalty to their workplace that makes them want to stay. Retention and recruitment of staff are achieved more successfully when the values of staff and the values of the organisation are compatible (Deutschman 2001). This may not always have been the case in some of the nursing homes in the study. The high turnover of staff was commented on by some relatives.

"It's a big home and they said oh... the same people will look after her all the time but that didn't happen...it would have been nicer I think if it had. But then staff don't stay very long in these places."

[Relative interview. NH.E: para.63].

This was a major challenge for the nursing home managers who, in independent nursing homes, were often trying to balance the costs of providing quality care as well as run a business. To fill the recruitment issue there was a complex array of different solutions that nursing home managers employed, some of which were quite temporary. Some had taken the step of advertising and recruiting nurses from abroad. Some staff were young and working between jobs and travelling. In one nursing home, many of the carers were Spanish students who were travelling the world after having been to university. Although the students were kind and even very interested in the study, they were only there for a few months and had left before the end of the study. In another nursing home nurses recruited from another European country were working as senior care assistants in order to experience the UK and learn English. Even those UK care assistants who did want to stay in the caring profession saw career development as moving away from the nursing home sector. Some appeared to undervalue the work they were doing. At the other end of the spectrum, many other care staff were in their fifties and saw themselves as beyond developing their care further, and instead, preparing for retirement. This high turnover of staff has major implications for the sustainability of any development or educational initiative.

ii Lack of a learning culture leading to a lack of motivation

In most, but not all of the nursing homes, time was not set aside for training. Except for one home, there was no overlap of staff in the afternoon; some nursing homes had changed to working a 12-hour shift pattern. An overlap allowed people to come to training but without this structure it was left up to the staff as to whether or not they chose to attend training sessions. It would appear that training is not something many staff, particularly carers, were used to attending. It was not seen as integral to their work but as 'extra' work. Getting the night staff trained was a particular problem, despite evening training sessions being held by the project team.

"...I've found some of the response to the training opportunities a bit...you know there wasn't the response I would have thought there might have been so I found that a bit disappointing, the numbers, I thought more people would have been interested."

[NHM. NH.H, final evaluation: para.131]

One carer observed that an interest in caring for dying residents has to be 'in your nature'. Another key champion observed that some staff might be frightened of the emotions raised by talking about dying.

The key champions themselves were affected by the lack of a learning culture in that some of them had to attend their 'action learning sets' (AL) in their own time. Sometimes they were unable to attend the set at all if their nursing home was short staffed. One of the difficulties of implementing an action learning programme is that it may not always fit the culture of the organisation. The values of the organisation can act as a barrier against the values that the AL aims to create. By this we mean that the values and beliefs inherent in AL (participation, learning, questioning and autonomy for learning) can sometimes be in conflict with some organisational cultures that are hierarchical and perhaps do not always seek to harness or encourage individual development. Some key champions found the lack of understanding from their colleagues about action learning difficult.

"It was really difficult trying to justify [AL] to people here because they had no, absolutely no concept of what use it could possibly be to effecting change."

[KC1. NH.C, final interview: para.118].

Boutall and Pedlar (1992:10) state that '*participants (in AL) need to be unafraid to pose difficult questions, and to arrive at original and potentially controversial answers.*' Although participants achieved this in the set, it was sometimes difficult for them to implement subsequent actions into practice. It may have been that we did not work together sufficiently long enough for major organisational changes to be made, or indeed, that we needed to consider whether an action learning set for managers may also have been useful in facilitating organisational change.

It could be argued that with the lack of a learning culture in an organisation, staff are less likely to be motivated to change or develop. There was always a greater number of staff in all the nursing homes who were happy with the 'status quo' even though there was a strong core of staff who were very keen to improve practice around end-of-life care. This may have been due to a lack of insight of the importance of death and dying in the nursing home, or a feeling that the care being provided was 'good enough'.

"...I mean [the NH] has always had a fairly good reputation and they couldn't see why there was a need to change what wasn't broken...so that was a big change, getting people to accept that maybe even though they are doing a good job, they could still do a better job."

[KC1. NH.C, final interview: para.219]

In nursing homes where this lack of motivation or resistance to change was compounded by other barriers, it was a significant obstacle to implementing the ICP documentation. For example, in one nursing home the ICP documentation was only filled in when staff who were interested in it were on duty. This lack of motivation to take part in the study was very frustrating for the key champions. The power of a disinterested attitude was very demoralising.

"...when people didn't cooperate... you felt ...ugh I'm just gaining nothing here, you're trying and you're motivating but nothing is happening... it just felt such a failure and it's so unnecessary..."

[KC. NH.G, final interview: para.63].

This particular key champion presented a situation at action learning where she described her frustration with other staff in the nursing home for not taking responsibility for starting the ICP and for not being an advocate for dying residents, particularly in getting 'prn' medication prescribed by the GP. She was finding she had to do it all with them. Through questioning at action learning, the key champion came to realise that even though she was doing the work with the other staff, there was no real opportunity for the other staff to learn formally from these situations, or to really understand the complexity of the actions of the key champion. So while it may have appeared on the surface to be a lack of motivation, this was in fact perpetuated by a lack of a learning culture.

At the beginning of the study the key champions were aware that unmotivated staff might be an issue, and even for those who overcame it, it was a fear.

"My initial expectation was 'I don't know if everybody will go along with this' ... I actually really feared failure ... if it did fail ... if people don't get on board what am I going to do. But as time went by I actually could see that no there was no failure, it was going to happen, one or two hiccups but still..."

[KC. NH A, final interview: para.130]

Features of a lack of a learning culture were apparent in the majority of homes. This is not an uncommon feature of nursing homes particularly around issues of end-of-life care (Hanson et al. 2002). However, the majority of the key champions were very motivated concerning the study and this motivation helped to secure, to some extent, staff interest, despite the relative lack of a learning culture.

iii Key Champion and Management Support Difficulties

Initially all the nursing homes had appointed two key champions who were responsible to act as the lead for the study in their nursing home. In those homes where a key champion left, it became very difficult for the remaining key champion to take on the sole responsibility for the study. This occurred in two of the nursing homes.

At the beginning of the study a decision was made to invite the nurse managers of each nursing home to select the key champions. With hindsight a greater dialogue concerning the selection of key champions may have been more appropriate. The degree of involvement that the key champions had with the study varied considerably across the nursing homes, and may have been related to the degree of interest in palliative care and/or how they saw their responsibility for practice development within the nursing home. Making the criteria for selection of key champions more explicit and appointing them 'jointly' with the nurse manager might possibly have highlighted the importance of the nurse manager's role in the study and made them more supportive of the key champions because of being more answerable to the core research team.

It became apparent through action learning that historically, changes in the nursing homes tended to be top down, with little or no consultation with the staff. Most of the key champions had no experience of implementing change or influencing policy. The attitudes that some key champions perceived the other staff to have towards them sometimes made it difficult for them initially.

"... I think it made other people think that we thought we were special...that was a negative thing... it could have been a negative thing but we got past that"

[KC2. NH.C, final interview: para.100].

Most nurse managers felt that they had given the key champions responsibility for the ICP study and felt this was a good development opportunity for them. The idea of having key champions implementing the change so that it was bottom up rather than top down, was beneficial in a lot of ways, one example being that they were approachable and accessible to all staff. Managers also felt it gave staff ownership of the study. However, in some cases it seemed that although responsibility for the study had been devolved, the key champions did not always have the power to make changes. As time went on both the nurse managers and the researchers realised that more input and support from the nurse managers was required. Nurse managers' attendance at the collaborative learning groups was an important aspect of this. One nurse manager, when asked if she felt there was anything she could have done differently during the study, reflected:

*"Perhaps if I had been more involved I would have been able to give more encouragement."
[NHM. NH.D, final questionnaire].*

There were some power struggles across the spectrum in the nursing homes, from powerful care assistants to powerful senior staff, GPs, and owners. The key champions needed the back-up of the nurse managers so that taking part in the ICP study did not become an 'optional extra' for staff, but rather an integral part of their work. A sense of powerlessness was often raised as an issue by the key champions at action learning sets. They often came to realise, however, that they did have some power and that there were things they could do to influence and bring about change.

3.2.2 CULTURAL BARRIERS AROUND DEATH AND DYING

This section focuses on the culture around death and dying in the nursing homes. It was the attempt to implement the ICP documentation which particularly highlighted some of these barriers, and they became areas which required development around end-of-life care.

i 'Striving to Keep Alive'

At the beginning of the study there appeared to be a 'striving to keep alive' model of care evident in the nursing homes. One feature of this was the appearance of the fluid balance and feeding chart at the bedside in most of the homes when the resident became frail and confined to bed. From the notes, it could be seen that these charts were filled in until the day the resident died, even when it had become clear that the resident was no longer swallowing because they were dying. It seemed that there was an unspoken expectation that good nursing care involved making people better by encouraging them to drink, even when they were dying.

*"Well I think it's just not 'striving to keep alive' which is what we have always done in the past, yes [the resident] will have a cup of tea and panicking if [the residents] don't have all [their] three course lunch. You know that we can say 'yes, you can die with dignity, we are not going to keep getting you out of bed and giving you your weekly bath' ...I think that is the biggest change for me."
[KC2. NH.C, final interview: para.219]*

Inexperienced carers would continue to encourage food and fluids because they thought that was what was expected of them. It was unsurprising that this happened since none of the homes at the beginning of the study included any teaching on care of the dying in their orientation of new staff.

*"...they are in here to die and it's such a big issue which is not approached in any way. When we do our training [orientation] it's not about dying, it's about how we toilet and make the beds in the morning and wash and dress them."
[CA.NH.G, VC group discussion: para.89]*

It may be that care standards which emphasise rehabilitation, and in particular monitoring the weight of residents, may lead to the inappropriate continuation of food supplements and referrals to dieticians. Weight loss is seen as evidence of poor quality care, but this standard is at odds with quality end-of-life care which accepts decline as part of the dying process (Teno 2003). Such standards may compound the feeling that the staff should 'strive to keep alive' those residents who were in fact dying.

For some people, this striving to keep alive went so far as to see death as a failure:

'You are there to nurse and make well.....we see people put a lot of effort in - it's almost like saying what we are doing is no good because if it was they'd get better'
[KC2.NH.D, ALS 3: para. 21]

This nurse knew in her head that the resident would die but felt uncomfortable saying it because she felt perhaps something could be done. McCue (1995) argues that death in our society is no longer seen as natural and expected but as a failure of medical care. However, as Smith (2000 p.129) observes *'If death is seen as a failure rather than as an important part of life then individuals are diverted from preparing for it and medicine does not give the attention it should to helping people die a good death'*.

This culture of striving to keep alive became a problem for some staff when a decision was to be made to commence the ICP documentation. Staff began to realise that when a resident was dying it was not appropriate to 'push' food and fluids. However, for them to stop this practice and openly say that someone was now dying seemed to be a significant barrier for them to overcome. Many staff in care homes are very attached to residents and know them almost like family (Moss et al. 2003). These close relationships were evident in all of the nursing homes in this study. Given this relationship between staff and residents it was often difficult to openly acknowledge that a resident was dying. There was a fear that starting someone on an ICP was 'giving up' or 'consigning someone to die' rather than acknowledging the natural process of dying.

'...you're not wanting to give up on them, you don't want them to go really, you keep holding on to their routine that little bit longer.'
[CA. NH.B, VC group discussion: para.89]

Sending residents to hospital very much seemed to be part of the 'striving to keep alive' model in one particular nursing home. Families were advised that if they wanted interventions such as oxygen or drips, then their relative would have to go to hospital because in the nursing home 'there is not much we can do, we can only give TLC and basic care'. There was a sense that no-one was recognising the dying process and coming to a decision that the resident was now dying (Forbes et al. 2000). Whilst this nurse recognised that the best place for the resident to die was in the familiar surroundings of the nursing home, her comments echo, perhaps unconsciously, the feeling described above that death is seen as a failure and that acknowledging dying is seen as giving up. Relatives sometimes seemed more ready than staff to recognise that there is a time to die.

"And then she would perhaps have a little milk or something one day and a little bit of food. And that went on for quite a long time and then she wouldn't drink either so that I think was when we realised. Well they said would we like her to go on a drip and we said 'no'..."
[Relative interview. NH.E, para.9-11]

ii 'Closed' Discussion around Death and Dying

It is difficult to be sure how much in-depth discussion about death and dying took place prior to the study between nursing home staff and families. Certainly, when the ICP was being considered there was sometimes a fear that the family would find out, and an assumption was made that they would be really upset that the staff thought their relative to be dying. However, using the ICP documentation did not guarantee that staff were confident about their extended psycho-social role with the resident and family. In one situation a resident's niece had visited and felt distressed by seeing her aunt now very poorly. Although nothing had been marked as a variant on the ICP 4hrly sheet regarding the resident's agitation, the nurse in charge of the floor called a locum GP in response to the niece's distress. The following excerpt is taken from the 'interdisciplinary notes' of the ICP documentation:

'Doctor arrived and gave [resident] a good examination - checked pulse, temp, respirations and sounded her chest; felt she was not in distress – was not aware of anything going on around her, not reacting to light shone directly into her eyes, his decision was good nursing care and let nature take its course. If she starts to get distressed not to hesitate to call the surgery for advice or another visit.'

[Excerpt from NH.A. ICP doc.No1]

The scenario shows the relative lack of confidence among some nurses regarding in-depth conversations around dying. Such conversations were something that many nurses felt was the doctor's job. Despite the ICP documentation, taking responsibility for the dying process was very alien to a considerable number of nurses and was something that the key champions had to work very hard at addressing with the care teams.

In interviews with relatives it became evident that they usually knew that their relative was dying prior to any conversations with staff. Where there was open communication this was appreciated as it gave them the opportunity to prepare and to be present if they wanted to be.

"...It was me who noticed the deterioration when we went on the Saturday, she died early on the [subsequent] Friday morning, I was visiting on the Saturday morning and I knew there was something not right then...they said 'don't worry she's fine we'll keep an eye on her'... 'cos I said to her my mother is dying, I was upset, and she said, 'she's probably got this bug that's going around'."

[Relative interview.NH.C, para.7-11]

It requires a lot of skill and confidence to discuss whether a resident might be dying. It seems that sometimes this discussion simply did not occur. Death just 'happened' with little planning around the event. There were many examples of how the subject of death and dying was taboo in the nursing homes and there was a lot of fear around talking about it. This was very obvious from the group discussions when staff talked about the removal of the body from the home

"It's finding the most secluded back door that you can find... that no one has to see it [the coffin]... you're trying to protect the families as well... it makes them realise, OK, [their own family member] is going to be dead soon and I think that's really, really quite difficult as well because you're trying to make them live to their fullest. And you know it could be a constant reminder, they're going to die soon sort of thing so I think its trying to protect the family as well as the residents."

[KC1. NH.D, VC group discussion: para.134]

Despite the fact that some people's desire to keep death hidden was to protect other residents and families, other staff were very uncomfortable with this cloak of secrecy. They felt that when someone died in their own home the body was not 'taken out the back door' so this should not happen with nursing home residents. Lengthy discussions occurred between staff about the hidden nature of death.

"I think it's wrong that they are shuffled out the back door, down the back stairs...why is it shuffled under the carpet, does this person not deserve the respect....."

[CA. NH.E, VC group discussion: para.80]

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 cheer them up or chivvy them along. Some staff seemed to find that this closed culture around death added to the strain of their job and was actually quite inhibiting, particularly when they had to deal with the other residents.

"If we knew they were told, we wouldn't walk on to the floor and think, does she know that such and such has passed away... we'd better not say nothing ... you feel as if they're out that back door and that's the last you hear of them, nobody mentions them... and you feel that some residents go back to their room and they sit and think about it...whereas you'd be better if you were open."

[CA. NH.D, VC group discussion: para.119]

This closed culture around death and dying further inhibited the recognition of dying and fostered an inadequate preparation for care in the last days of life. Without this preparation it could be argued that a 'good death' becomes a chance happening (Smith 2000).

iii Difficulties in end-of-life decision making

end-of-life decision making and recognising that a resident is dying is not necessarily straightforward especially with the prolonged dwindling dying trajectory of most frail older people, particularly those with a diagnosis of dementia (Lynn & Adamson 2003). Within the nursing home setting most nurses will know the resident much better than the GP. However, at the commencement of the study, even when a nurse knew that a resident was dying, they often would not want to influence a GP's decision. Instead they would 'meekly go along' with the GP's suggestion, even to the detriment of the resident. There were a number of situations where this was highlighted.

'The staff had sent for the GP thinking that he would say 'enough is enough' and they would then think about the ICP. 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 little contact with family – the nursing home staff were family. The lady died in an alien environment much to the dismay of the staff'

[ALS3. NHD/H, para.21].

Through further exploration of this scenario in action learning, it transpired that the key champion had actually said to the GP 'I don't know what more we can do?' She was able to reflect that the GP may have interpreted that as the nursing home staff wanting active treatment. The key champion and the GP had a 'corridor chat' and the options that were available to the resident were not made explicit. The key champion came to realise the importance of the wording of requests to the GP, and also the importance of thoughtful and respectful decision making which recognises the value of the resident's life. Given the opportunity to explore situations such as this at action learning, key champions and the project team came to have a better understanding of the barriers which needed to be overcome. Such an incident generally motivated key champions enough to develop specific strategies to minimise the chance of such a thing happening again.

However, sometimes it was also a lack of communication about end-of-life care that clouded end-of-life decision making, causing confusion and anger not only amongst staff but also relatives.

An extract from fieldnotes [NH.G, para.17]

'Care assistants (CAs) mentioned they had a person with dementia (just like 'Molly' in the scenario that they had been working on to learn more about the ICP documentation). This particular resident had been started on antibiotics last night despite the resident telling care assistants she wants to die. CAs very upset by it all. Talked with key champions and a staff nurse came off the ward to explain the situation - the resident had had oral morphine prescribed yesterday and was felt she should be allowed to die but the 'late shift' had a GP come out. The GP 'on-call' didn't know the resident and he started antibiotics and a steroid The resident was described as 'all skin and bones' & had actually said herself that she wanted to die. Resident's son arrived this afternoon from down south – very unhappy that their mother has been given antibiotics. Staff nurse phoned the GP for further discussion but GP was not prepared to go against another GP'

Nursing homes are not like hospices where there are doctors on site most of the time. In nursing homes, nurses are isolated and carry a lot of responsibility for all decision making. They are very aware that GPs have a heavy workload and it seems that there can sometimes be an attitude of 'not wanting to bother the doctor'. If there is not a good working relationship with the doctor, exacerbated by the fact that as many as seven GP practices can cover the medical care of residents in any one home, this adds to this reluctance at times to phone the GP.

"I think you also get into this 'Oh you can't phone the GP' ...I think you should be able to phone the GP any time because after all [the residents] are still human beings they should not have to die in pain or distress... I wouldn't think twice about phoning a GP but there are people who don't do it... there's this big stigma, 'the GP's busy', 'they've not got time', or 'it's a locum they don't know', but I just think they should."

[SN. NH.C, VC group discussion: para.110]

Even when GPs were very helpful and staff in the nursing home had a good rapport with them, there was still sometimes a reluctance to upset the status quo.

An extract from fieldnotes [NH.B, CLG: para.32]

'One of the carers during the session felt there was a resident who was ready to go on an ICP. [Staff nurse] asked but not sure yet. Apparently, the nephew has asked for antibiotics to be started. The resident is 94yrs old but "the nephew wants to do everything he can for her since she did everything she could for him after his parents split up when he was young." GP was in while I was doing a teaching session and I was told "has started antibiotics - can't see any reason for the deterioration but thought he would try antibiotics!"

Another contributing factor to the nursing home staff's lack of confidence in end-of-life decision making was their feeling of 'being in the dark'. Many nursing homes do not have access to medical notes or much background information on the residents and rely on this information being passed to them by the GPs. If there is no regular weekly/bi-weekly meeting this background information can be lost.

Because the implementation of an ICP demanded open communication about death/dying between nursing home staff, GPs, families and residents, this culture of 'striving to keep alive', not talking about death, and the reluctance to take responsibility for end of decision making, all became very real barriers. A lot of guidance and education was required as part of the process of implementing the ICP documentation to overcome the barriers.

3.2.3 CLINICAL BARRIERS

This section looks at issues specifically around the lack of knowledge of palliative care among the multidisciplinary team in the nursing homes which acted as barriers specifically to the implementation of the ICP documentation.

i 'Imminent dying' not recognised

Quality end-of-life care which allows the opportunity to prepare for death is increasingly recognised as an ethical obligation of health care providers (Singer et al 1999). This underlines therefore the importance of recognising dying. The dying trajectory in old age is much more unpredictable than the dying trajectory of cancer patients in mid-life (Lynn & Adamson 2003). With frail older people dying at the end-of-life from multiple medical pathologies, the unpredictability can become a barrier for staff making a decision about dying. The chronic illness trajectory can in fact disguise the dying process (Forbes 2001). At the beginning of the implementation of the ICP study, staff often said that they had not had time to start an ICP because the resident had died very quickly. Not using the ICP documentation meant that a certain amount of momentum of the study was lost.

Experienced nurses who know the resident well are often the first to recognise when a resident is dying (Blackburn 1989). A few nursing home staff in this study were often very astute at recognising when someone was dying. Unfortunately they were not always listened to by the GP.

*"...the man that died in here 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 for nothing. He wasn't out the door 15 minutes and the man had died. And I thought that was ridiculous...he said oh just double his antibiotics you're getting in a state about nothing."
[SN. NH.G, VC group discussion: para.48]*

Some issues presented at action learning highlighted that there was often disagreement within the team about whether someone was dying. This disagreement could be between nurses, between carers and nurses or between doctors and nurses. Some key champions found it difficult to bring about changes in end-of-life care when there were other staff members who had very strong opinions about issues related to end-of-life care, for example, hydration. These disagreements were often very emotive.

Lack of knowledge on the part of GPs to recognise imminent death also meant that some families were told their relative was going to die long before the event actually occurred. This prolonged anticipation of the event created a lot of anxiety for families

*'...it wasn't as if she was in her bed and was ill she was up and about, she was eating really well, her appetite was excellent,...we were beginning to question, why did he paint this black picture"
[Relative interview. NH.D: para.89]*

At the beginning of the study the knowledge around end-of-life care was so limited in some of the nursing homes that often it took a number of ICP documents to be used before staff became more attuned to the process of dying.

ii Lack of knowledge of palliative care drugs

A further barrier to the implementation of the ICP documentation was the lack of knowledge about the drugs available to relieve symptoms at the end-of-life. When commencing the ICP documentation, one of the main features of the initial assessment is to score off unnecessary medication alongside the prescribing of 'prn' medication in anticipation of any agitation, respiratory secretions or pain. The only drug that was regularly used across the nursing homes in the last days of life was oral morphine, whether or not residents were on a previous opioid analgesia. However, the loss of the swallowing reflex in dying residents was rarely anticipated; thus, subcutaneous or rectal medication was rarely prescribed prior to the implementation of the ICP documentation. Terminal agitation is a common symptom especially in situations of agitated delirium as a result of a disease such as dementia (Hall et al. 2002). In such situations, medication that the resident has previously been given to help them feel less anxious needs to be continued when they no longer can take their oral medication. In this study, such anxiolytics were rarely continued. Agitation was not an uncommon symptom for a resident who was dying. Many carers and nurses related that that was an expected part of the last few days of life. Some even had their own name for it – *"the terrors"* [CA. NH.C, VC discussion group: para.131].

"...nobody should have to die in pain. And fear as well. A lot of it is fear as well and distress. Not even necessarily always pain..."
[SN. NH.C, VC discussion group: para.121].

There was little anticipation of respiratory tract secretions as a complication in the last days and the benefits of using an anticholinergic in such a situation were unknown. Drugs such as s/c midazolam, s/c levomepromazine (methotrimeprazine) and s/c hyoscine - drugs all important to delivering quality in end-of-life care - were rarely used even as 'prn' prescriptions in the nursing homes prior to the ICP study.

"It's quite amazing really when you think about it, all the deaths that I've seen and that's a lot, I have never seen [midazolam or hyoscine] prescribed by a GP."
[SN. NH.F, final evaluation: para.107]

Not all older people in their last days of life however suffer each and every symptom. The importance therefore of 'prn' medication, such that a drug can be administered at the first sign of distress was crucial, and when it was not readily available, often caused considerable anger and frustration for the nurse.

"If you could get something set up so that we feel, oh well we've got that PRN ... without having to phone the GP, or wait till the next day...and by that time then they've maybe got only an hour or so left. It's distressing for relatives to come in and see their mum or their dad or granny or whoever."
[Night Nurse NH.C, VC group discussion: para.29]

Prescribing drugs in anticipation of a symptom at the end-of-life was an alien concept to some GPs. Many argued that if a symptom became a problem then a doctor would come out and prescribe a drug. Little thought was given to who would be available to get the drug in the middle of the night or at week-ends. The other argument given was that if the prescribed 'prn' drugs were then not required they would then have to be discarded and money wasted. However, the financial implications are negligible compared to the unnecessary length of time a resident might have to wait, and the disruption to busy nursing homes if the limited amount of medication is not anticipated. Current law states that nursing homes, unlike hospices, are not licensed to hold stocks of dangerous drugs unless they are for a named resident.

Staff working in nursing homes are isolated from much on-going education other than that which is statutory (Gibbs 1995; Katz et al. 2001). However, it was also evident from this study and from the field note extract below that some GPs lacked knowledge about drugs at the end-of-life.

An extract from fieldnotes [NH.D, para:1]

The lady who was dying had been quite distressed during the morning and they had phoned the GP to say they thought she was in pain. The GP had told them to give the resident Cocodomol despite the staff saying she could not swallow. He then decided to give her s/c diamorphine. While I was there the person who had gone for the prescription came back and it was oral morphine that had been sent. The manager phoned the GP again and said the resident could not swallow. The GP said he would write up i/m cyclimorph. Then he phoned back and said he was not happy to prescribe i/m cyclimorph and was thinking about what dose of s/c diamorphine to prescribe. By the time the medication arrived the lady had settled and they decided not to give it unless she was agitated again.

It must be acknowledged that GPs may only see a few deaths each year, and thus may not have the opportunity to become knowledgeable in palliative care. They are also working in a wider culture where there is currently an element of fear around prescribing opiates – exacerbated by the Shipman inquiry (Mohammed et al. 2004).

The difficulty in not being able to differentiate between what was agitation and anxiety and what was pain was a common problem. There were examples of opiate naïve residents being prescribed a Fentanyl patch when they were dying. There was little understanding amongst both nurses and GPs of the consequence of opiates being used to 'settle' a resident in the absence of pain. In one particular situation the nurse did not feel 'believed' when she was trying to convince the GP that the resident was hallucinating as a result of an increasing number of Fentanyl patches. The nurse was so concerned that the only way she could manage to get the increasing Fentanyl stopped and some Diazepam prescribed was to send the family to the GP practice to make the GP listen.

The lack of knowledge on the part of a majority of GPs and getting them on board with the ICP study was a major barrier in developing practice in relation to 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 organised and 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."

[KC1. NH.C, interview: para.158]

It proved extremely difficult for the key champions in each nursing home to arrange meetings with the GPs to explain the ICP documentation. This problem was again exacerbated by the issue of nursing homes using multiple medical practices.

3.3 FACILITATING FACTORS

Some nursing homes were more 'successful' than others in terms of the number of ICP documents commenced and completed. However, significant developments in end-of-life care resulted in a couple of nursing homes despite staff only managing to complete one ICP. It was necessary therefore to understand factors already present within the nursing homes which would facilitate the implementation of the ICP documentation and the development of end-of-life care. It is also necessary to understand the factors that make a change successful if it is to be sustained (Redfern et al. 2003).

3.3.1 The unique relationship that staff have with residents

Staff in nursing homes tend to form strong relationships with their residents (Irvine 2000). It is this unique relationship that can hinder but also facilitate care in the last days of a resident's life. Many care assistants give a lot of the hands-on care, and they are often the first to recognise when a resident is becoming frailer. At the commencement of the study, because the care assistants lacked formal knowledge and confidence in their own abilities, their thoughts were not vocalised and they relied on trained staff to take the lead. When the intuitive knowledge of the carers was formalised and given recognition (brought about through involving them in the study and encouraging them to use the ICP documentation), they became instrumental in facilitating the implementation of the ICP documentation. The following excerpt from field notes illustrates how the carers were very 'in tune' with residents

An extract from fieldnotes [NH.G, para.113]

While working through the scenario [at the ICP education session], one care assistant was particularly interested as she felt it described a resident on her unit. After the teaching she was enthusiastic enough to stay and talk with myself and the staff nurse about the resident. She said that it described the resident perfectly. She as an untrained carer was applying 'diagnosis of dying' criteria and felt this person was dying. Chatting with the staff nurse he was clearly 'anxious' about starting the documentation. Said he would speak to the charge nurse in the morning. The charge nurse duly phoned the GP and asked him to visit after the week-end - but he said that the resident had another 2 months to live as they still were quite fat. As it happened the resident died later that week within 5 days of the GP seeing her. The care assistant was right!

The strong relationship that staff have with residents means that within the nursing homes there is a real desire that residents will have a 'good death'. In all the nursing homes there was at least a core group of people who were very interested in the care of the dying and had a real desire to get it right. In this study, these staff were very faithful in attending all group sessions and they were a crucial element in the successful implementation of the ICP documentation.

"I be more upset if I've not been on shift...honestly, because you have been dealing with that resident for so long you want to care right to the end and make sure that everything's done absolutely perfect."

[CA. NH., VC group discussion: para.150-154]

3.3.2 The role played by the key champions

The presence of key champions within each nursing home was a vital part of the project design and crucial to any developments. The characteristics of the key champions in the nursing homes where there was most 'success' included:

- previous palliative care education
- an enthusiasm for palliative care
- an ability to think critically and respond well to action learning
- a clear grasp of the scope of their role including an interest in practice development
- the ability to work proactively
- a level of respect and credibility within the nursing home
- persistence and commitment
- the ability to motivate others

Those who were most successful at embedding the ICP documentation into the organisational culture of the nursing home were those who spent time preparing staff, explaining the paperwork, encouraging them to come to meetings and to complete questionnaires.

"The outcome is the motivation of the staff, the involvement of everybody, the way I've managed to sort of get everybody maybe responding to questionnaires and whatever issues that linked to the ICP... it's not as straightforward as it looks...you just need to be proactive and mean what you say and keep on going ...filling in the ICPs I had to sit down with some carers and just go through it ...you just have to continuously go back and repeat yourself on quite a few things and sometimes it can be very frustrating because you're thinking I'm coming back and I'm doing the same thing again and again..."
[KC. NH.A, final evaluation: para.9 -33].

Although this level of commitment was not easy for the key champions, it did mean that others in the nursing home became motivated and developed expertise in end-of-life care.

3.3.3 Facilitating factors within the organisation

The carers and the key champions were instrumental in all of the homes but other key factors in the context of the nursing homes which were important included: the interest of the GPs; the presence of a learning culture; the readiness or openness to change; the degree of management support.

The following case study of a 'successful nursing home' highlights the key elements which, combined, contributed to their success (see Table 3.2).

Table 3.2: Case Study NH.E

<p>Key champions (KC)</p>	<p>One KC had done a palliative care course. Both KCs passionate about palliative care, highly motivated and committed to the study. Both respected within the nursing home. Both KCs were critical thinkers and responded well to action learning. They worked well together and supported each other. Took the initiative to prepare staff before the study officially began. Organised and facilitated fortnightly training sessions throughout the year of the study so that all new staff were fully informed about the study and the ICP documentation.</p>
<p>Learning Culture</p>	<p>Active learning culture – regular time set aside for different training. Overlap of staff in afternoons to allow for this. Key champions given study time to attend action learning. Evidence of ongoing commitment to staff development – appraisal scheme, employee of the month scheme. Forums for discussion e.g. monthly carers meeting.</p>
<p>Management support</p>	<p>Nursing home manager committed to monthly meetings with researcher/CNS and KCs. Attended a number of CLG sessions. Supported KCs by giving time to organise training and attend sessions. The nurse director of the whole company was extremely supportive of a learning culture and palliative care</p>
<p>Support of other staff</p>	<p>Night coordinator with palliative care experience – trained the night staff. Other senior staff very committed – took on facilitating role when key champions not there. Strong group of very committed carers. Very good attendance at all sessions throughout the year.</p>
<p>GP from one practice for the majority of residents</p>	<p>GP had built up trusting relationship with staff and KCs. Regular visits to nursing home – came to initial meeting about ICP study - frequent exposure to ICP documentation and cooperation with study. Established relationship with study coordinator. Attended a CLG session. Instrumental in setting up a meeting and getting other GPs in the practice 'on board'.</p>
<p>Readiness to change</p>	<p>Recognition of need to change - experienced some 'bad deaths'. Staff had requested palliative care training - already had links with local hospice.</p>

3.4 SUMMARY

This chapter has detailed the context of the nursing homes taking part in this study. It has highlighted barriers to interventions to develop end-of-life care in the nursing homes and also the factors within the nursing homes which facilitated this development.

We would suggest that the ICP for the last days of life documentation makes a number of assumptions. These assumptions underpinned the barriers outlined in this chapter which became apparent when an attempt was made to implement the documentation. These assumptions are:

- that nursing home staff know when someone is dying and understand the dying process
- that nursing home staff are familiar with palliative care drugs
- that nursing home staff are confident in communicating about dying
- that there is good multidisciplinary team working in nursing homes

There was also an assumption about the willingness of the nursing homes to change – this had been something that we had tried to address in the criteria at the beginning of the study. However, the culture sometimes militated against the change.

It is important to say that individual barriers in themselves might not prevent implementation of the documentation and the development of end-of-life care, but where there was an accumulation of a certain number of these barriers it was more difficult to effect change. The cultural and clinical barriers were overcome to some extent in a majority of the nursing homes. However, these barriers highlighted issues around end-of-life care which required development. This ensured that the education given was grounded in staff need rather than anything imposed by the 'core' research team. The organisational barriers were much more difficult to address. Within the scope and timescale of the study, organisational barriers were really only beginning to be addressed in some of the nursing homes.

Although not overtly resistant to change, many of the 'barriers' highlighted within the nursing homes compounded to make the 'context' of some nursing homes rather weak. However, weak contexts may be overcome by appropriate facilitation (Kitson et al. 1998). The facilitating factors within in each nursing home as outlined above counteracted some of the barriers described. The process of developing end-of-life care and the way in which some of the barriers were overcome by facilitating factors from outside the homes (action learning sets, collaborative learning groups following a death, clinical nurse specialist advice alongside the use of the ICP documentation) is described in the next chapter.

Chapter 4

Processes assisting the implementation of the ICP documentation as a tool to develop practice around end-of-life care

The processes involved in bringing about change are vital not only to any 'outcome' of change but more importantly to the sustainability of that change. This chapter examines the deliberate facilitating strategies employed in this study to promote end-of-life care in the study nursing homes. These comprised:

- Facilitation through action learning 'sets' to support the key champions in implementing the ICP documentation and developing end-of-life care in their nursing home
- Facilitation through 'collaborative learning groups' to support all groups of staff in each nursing home following a resident's death, alongside the use of the ICP documentation
- Facilitation through the role of a clinical nurse specialist in palliative care

4.1 FACILITATION THROUGH 'ACTION LEARNING'

Action learning is a process of learning and reflection that happens with the support of a group or set of colleagues working with real problems with the intention of 'getting things done' (McGill & Beaty 2001).

4.1.1 Rationale for use of action learning in this study

The process of action learning was used in this study for the following reasons:

- It offered the opportunity for practitioners to understand not just how the ICP document fits with practice, but the processes of implementation, including the cultural and organisational barriers, that need to be challenged to bring about effective change. Organisational and cultural barriers are complex. The strength of this approach is that the focus is on real problems that do not have clear solutions. Supporting participants in the study to make sense of the messy world of practice was a priority. Weil (1998) talks about the importance of working with continuing contradictions as a way of carrying us beyond superficial learning.
- It addressed the need identified by Kitson et al. (1998) to incorporate appropriate facilitation into any model of evidence into practice. The facilitator's style is crucial to adopting a model that achieves critical reflection, in that there must be an emphasis on enabling others, rather than doing for others. Facilitators in this study had significant experience of action learning.
- It provided a process where values and beliefs that underpin actions related to end-of-life care and bringing about change could be explored. Marsick (1990) talks about bringing real issues to the fore and subjecting them to scrutiny - allowing participants to call into question the rationale underlying their actions, and to examine problems from multiple perspectives. Questions used in action learning particularly relate to probing assumptions and encouraging empowerment. Underlying the approach to action learning is that of critical reflection. This means that participants need to reflect not only on their experience but on the assumptions and beliefs that shape practice (Marsick & O'Neill 1999). This was crucial if real change was going to be realised in this study. The philosophy underpinning action learning is that of critical social theory. Given the context of nursing homes described in the previous chapter, it seemed appropriate to use an approach drawn from this theory, since *"the advantage of critical social science for nursing and nurses is that it*

offers the opportunity to shatter the ideological mirror that traps us and our clients...It forces us to question the status quo at every turn creating a culture of critical inquiry" (Allen 1985, cited in Graham 1995:31).

- It addressed some of the issues around sustainability in this study. Participants were required to bring to the set issues that they found problematic and wished to explore further, in order to learn from these experiences. Thus the learning was grounded in real events that had happened previously. Revans (1998) suggested that sustainable change is more likely to occur through re-interpretation of previous experience, rather than just simply acquiring more new knowledge.
- In addition, it offered the researchers an opportunity to collect relevant data about the process of change for the evaluation and to give something back in the form of facilitated learning to the participants. In studies where in-depth interviewing is the main source of data collection, it may be possible through careful questioning to get at the heart of issues by challenging assumptions, beliefs and values, but the purpose of doing this is to gather rich data rather than to help the person learn from the reflective experience in a deliberate way. The interviewer in this situation may not have a responsibility to help the person learn from this situation and consider other options and actions.
- It provided a process whereby participants were enabled to make their learning deliberate. Two specific learning needs of participants in this study could be said to be learning for the study and learning from the study. Action learning enabled both types of learning to take place.

4.1.2 The integration of action learning (AL) into the study:

The following values that underpin action learning identified by McGill & Beaty (2001) formed the basis of the approach we adopted in this study:

- Through reflection we learn from experience
- Set members offer support and challenge
- At the centre of the set process is empathy
- The individual is empowered
- Quality of attention to the presenter and their issue is an important aspect of the AL set
- Trust and confidentiality are important to the AL set
- Development takes time (AL sets lasted over a number of months)
- A holistic approach means that the process involves taking into account the thoughts and feelings of the individual as well as the tangible results of their actions
- It is voluntary

In relation to this last point regarding the voluntary nature of the group, it should be emphasised that participants consented to take part in the study as a whole. Only once they had given their consent were they informed that action learning was a key element of the study. They had no previous knowledge of what action learning was about and therefore although they consented voluntarily to the study it could not be assumed that they had signed up to action learning on this basis. We therefore needed to check out with them at several points throughout the course of the study if they were happy about progressing with action learning. The majority of the participants were keen to progress and made every effort to attend all of the sessions. One participant had a low attendance and her comments in the final evaluation reflected her dissatisfaction with this approach to learning.

Most of the key champions identified action learning as being necessary to support them in their role to implement the ICP. All except two made attending the monthly action learning sets a priority. Participants in an action learning set each present an important issue and are actively supported by other members of the set. The process helps people to take an active stance towards life, and helps overcome the tendency to be passive towards the pressure of life and work (McGill & Beaty 2001). The process is intended to develop both the individual and the organisation. [See Chapter 2 for method around the organisation of action learning sets].

4.1.3 Key Issues to emerge from the action learning sets

A range of issues were presented at set meetings. Participants were encouraged to bring an issue they wanted to explore further and it was agreed that this did not solely have to centre around the implementation of the ICP documentation. Initially, this surprised the participants, but all except one thought this was the strength of action learning, with the emphasis on challenging aspects of the organisational culture.

*"...That made it better in a sense that it was more realistic ...you felt oh yes everything is being sorted and looked at
[KC. NH.G, final Interview: para.25]*

Some of the sessions did focus on the ICP, whilst others focused around more general issues that affected their working practice in the nursing home. Irrespective of the focus of the presentation, efforts were made to ask the participant if they could transfer any of their learning to their work with the ICP study. Often they were able to do this as the learning frequently focused on managing people, becoming more self aware, and dealing with power issues. Many of the issues identified in the sets were leadership issues. The case study (Box:4.1) taken from field notes during action learning, illustrates some of the issues around building working relationships, as well as some of the underlying values and beliefs that inform action.

4.1.4 The importance of addressing feelings in the learning situation:

In action learning exploring how people are feeling about a particular experience is central to the questioning. Indeed the process of action learning is intentionally iterative, moving between the objective world of things and the subjective world of feelings. It works on making explicit links between them. Although this may at times be uncomfortable, it is argued that this is important to move forward genuinely (Walker & Dewar 1999; Salmon 1988 as cited in Weil & McGill 1989). Feelings of anger, disappointment, frustration, excitement and sadness were some of the feelings that were shared. The following excerpt from a presentation illustrates some of these feelings:

'The presenter talked about her feelings of guilt at not being able to implement the ICP. They are very short of trained staff and do not have the time to do it. She wants to do the ICP properly but the GPs are not yet on board and the night staff have not been trained. Other trained staff do not want to use their initiative to start it. Some of the other staff are not comfortable with talking to families about dying they pull back from it and are sometimes not realistic. They do not have a passion for care of the dying. Although the presenter feels she has a clear conscience in giving the best general care, she feels very sorry and that they have failed when they have not implemented the ICP on time. This really bothers her as she feels they are not doing well enough with the ICP. She feels they are part of the project and would like to be able to 'deliver the goods'. They have become more aware and now 'really try to look at the bigger picture and we really have done better and better by the resident but it is the documentation'. She feels it has been a battle because she is on her own without support. Her manager was positive about it at the beginning but is very busy and just doesn't think about it.'
[KC. NH.G, ALS2: para.24]

Box: 4.1 Action Learning case study

Case Study 1:

The presenter described a situation where she had difficulty getting the GP to sign up to PRN medication. The presenter finds that most GPs are fine with starting the ICP and scoring off non essential medication but are reluctant to write up PRN medication. The GP usually says 'see how it goes'. The 'out of hours' service in this nursing home carries a stock of PRN medication but the presenter still feels it would be better for them to have the prescriptions in advance, particularly since the condition of the resident can change so rapidly and not having PRN drugs available can cause a delay of several hours. The presenter was asked to think about possible reasons why GPs may be reluctant to prescribe the drugs. She felt part of the reason that GPs are reluctant is that they don't want to waste money if the drugs are not used. She also thinks that they are reluctant because they see starting someone on an ICP and then writing them up for diamorphine as being like a self fulfilling prophesy. She felt that it may also be because the GPs did not trust nurses to make decisions about this medication. She said that, one GP had said to the presenter that you can't just give diamorphine. She felt irritated by the judgement the GP had made on the nurses ability to give this medication. She was then helped to explore the evidence that she presents to GPs to articulate decisions about end-of-life care, medication and the nurses role in this. The presenter was encouraged to think about her language when asking for particular medication requests, and to reflect on the extent to which she uses language that promotes collaborative working or confrontation. In doing this she also began to consider how the GP might feel during these interactions and felt that perhaps GPs feel threatened by nurses saying 'this is what we want'. The presenter came to realise that she was making a lot of assumptions about why GPs were reluctant to prescribe PRN medication. She was encouraged to think through how she could present evidence to GPs of where PRN medication had been beneficial, particularly how good it was to be prepared with hyoscine when this resident went on the ICP for the second time. In the past she felt that she had been reactive and found that very frustrating.

Action Points

- To have another meeting with the GPs to discuss the ICPs they have had so far and to present evidence about the difference this had made to resident care
- To ask the GPs their concerns about anticipatory prescribing and to try to take them a step further by starting with hyoscine rather than going for the whole package.
- To try to present GPs with evidence of why PRN medication is useful to NH staff
- To consider communication strategies that would help promote the concept of the ICP as 'integrated' & to think of the team rather than 'us & them'
- To consider producing a decision making tool about medication use, to guide inexperienced nurses and to reassure the GP's about nurses actions

Themes

- Difficulty of fully implementing the ICP when a range of stakeholders are involved
- The need to know the opinions of the GPs about the ICP, particularly PRN medication
- The importance of producing evidence to support arguments for change
- The 'integrated' nature of the ICP
- Importance of articulating the benefits of using the ICP
- Importance of not making assumptions
- Importance of ongoing dialogue in the team
- Importance of building up a trusting relationship

[ALS.3R: D & H]

For many it was the first time that they had articulated what they had felt about an experience. The articulation and sharing of this often moved the person from a state of equilibrium to disorientation as described by Taylor (1987). Through careful supportive questions presenters were helped to explore these feelings and to develop an understanding of what these feelings represented.

"There's not a right and wrong. It's about looking at the bigger picture. It's also important for me to bring in feelings – in nursing you don't really go down that road... Also the things I presented, the difficult death, exploring that...I could list things I could do in the future. It shifted feelings I had carried for a long time."

[KC2. NH. E, ALS evaluation: para.11-36].

The state of disequilibrium brought about by asking about feelings was not welcomed by all participants:

"I'm a very introverted person by nature...and I felt very uncomfortable and I thought a lot of that stuff in the group ...it really made me, I really didn't like it. I didn't mind listening, if people want to open up and talk that's fine but it's not for me. It really made me very uncomfortable... I felt if it had been more clinically geared, that's fine and maybe I lost the concept altogether but I really didn't understand it..."

[KC. NH.B, final Interview: para.151].

It is emphasized that during any presentation the presenter has the authority to take control of the session and can choose not to answer questions and to be specific about what they would like to get out of the session. This can however be difficult to sustain. The above quote emphasizes the importance of the voluntary nature of action learning.

4.1.5 Key benefits of this approach to learning as identified by the key champions

i Taking responsibility for learning

The main function of set members in an action learning set is not to offer advice, but rather to help individuals to understand their situation better, by exploring through reflection, and to challenge assumptions underlying these reflections in order to decide the best course of future action. In other words, part of their role is to help individuals to take responsibility for their learning. Covey (1989) observed our tendency to project our own biographies on what we think people want or need and how we project our intentions on the behaviour of others. Participants found it challenging to refrain from giving advice to others during the set, but saw the value of this when they were the presenter, that is, the person in receipt of this advice:

"With action learning, the way I see it, you are coming to your own conclusions, nobody comes and says do A, B, C. But maybe that's because the things we've discussed don't have A, B & C to sort out. Its by talking through you see another way...and come to your own conclusions, rather than somebody saying do this."

[KC2. NH.D, ALS evaluation: para.1].

"I thought it would be just discussing the ICP, so it was more empowering, empowering me really as an individual to be a listener and to be able to sort of, you know, help somebody through, not leading them but, helping somebody to help themselves."

[KC. NH.A, final evaluation: para.97].

Not all of the participants in the study welcomed the opportunity to engage with this type of learning, which then appeared to impact on the motivation of the key champion which in turn further impacted on the study:

"I went along probably with the wrong expectation because I really thought it was going to be all the people from the nursing homes talking about their experiences with the ICP, the documentation, the problems they were having with GPs all these things that we can really empathize with each other, and did somebody have a solution."

[KC. NH.B, final evaluation: para.173].

ii Increased ability to question

Many of the participants felt that they had learnt more about the skills of listening and asking questions. Revans (1998) highlights the importance of being able to pose questions about one's practice world in order to change it. Key champions had begun to see the value of this, not just in the action learning process, but in their practice:

"Good questioning is very valuable in all aspects in any conversation. The use of good questions is very thought provoking."

[KC1, NH.D, ALS evaluation: para.69].

This participant talked about how she is using questions much more when she has student nurses in the care home.

iii Tackling the issues of power in the organisation

Some writers (see for example Fenwick, 2003) have criticised action learning for focusing too much on individual learning, and not challenging the prevailing organisational structures of inequity, nor addressing the contradictory power relations that may also obstruct emancipation in organisations. The issue of power was raised frequently in set presentations. There were examples of decisions being

made within the organisation without consultation of key individuals. The action learning did help individuals to recognise that this was happening and to realise the power that different stakeholders had within the nursing home and how they could use this to their advantage.

The extent to which the key champions were able to change the power dynamics within the nursing homes, or indeed change the organisational culture was perhaps more limited in this study. More time would have been required, together with a stronger commitment from management to this process if these contradictory power relations were to be fully challenged.

iv Learning from sharing with others

Action learning enabled participants to exploit their shared learning across projects in the different nursing homes.

"I think the whole project has helped me, coming here to do the action learning as well, it has helped me because I felt I could speak to other nurses from different areas who were able to sort of share information openly. And I felt, what can stop us doing the same thing in our nursing home, to be sharing information openly about the care of our resident so that sort of helped me."

[KC. NH A, final interview: para.65]

"It's been really good having the relationship with the other care homes, hearing about what others are doing and drawing on their experience."

[KC1. NH.C, ALS evaluation: para.91].

"The fact of the moral support and the fact of the shared problems and you felt oh well I can give it a go again let's go and try again because this is happening there and that is positive there..."

[KC. NH. G, final interview: para.29].

This sharing did not only have benefits to the individual participants but for the research study as a whole. Some of the learning and resultant action that emerged from one participant's presentation was relevant to others in the set.

v Transferring learning to practice

During the action learning process participants are facilitated to identify their significant learning. Through the process of doing this they are then more able to translate this experiential knowledge into knowledge that is then available for application to other situations. Evans (1992) would argue that such a progression is necessary for the development of transferable skills. Participants were able to identify some of the skills they felt they were now using consciously in practice, particularly in relation to the ICP study. These skills tended to focus on more effective communication:

"...when I came to try to apply the techniques that were being used, it worked out for me, it worked out quite well, because it actually made me listen to carers, ..., it actually made me think when somebody came and asked me, 'why is it written this way?'...it made me talk about it instead of me just saying that's the way it's meant to be and that is the way you are supposed to do it."

[KC. NH. A, final interview: para.117].

" It's the importance of taking time – my mind moves so fast and becomes tangled...it's taking time to untie the knots....also confidence in presenting, that's what I've taken into my work."

[KC1. NH. E, ALS evaluation: para.57].

Fish and Purr (1991) argue that by engaging in the reflective process of action learning, in relation to the person's own experience, people can begin to understand how to facilitate this process in others.

Some of the participants did feel that they were asking different questions in their areas of practice.

"One of the things that I presented about doctors walking off, well next time ...and another couple of times, what we talked about I did it. I felt it made it better, it was more a team discussion. I felt they were more involved rather than saying do A, B & C and walking out."

[KC2, NH. D, ALS evaluation: para.57]

"People have noticed that in me at work. I'm reading things differently, looking at things from different angles, more laterally."

[KC. NH. F, ALS evaluation:para.14]

" Self awareness. I now take more time before I jump in with advice or judgement. I'm more facilitative and reflective with staff and myself. The process (of action learning) has made it obvious how important the process is – it is critical to how it has gone – the structure and the groundwork – it wouldn't have been so successful."

[KC1. NH. C, ALS evaluation: para.53]

For another participant she felt that the process had helped her to change her attitudes about the GP and how she perceived and understood things. She went on to suggest that she has become more aware with how she is in a team.

4.1.6 Developing new theory

Kolb (1984, cited in Burnard 1987) identifies how reflection on an experience can lead to the emergence and development of new theories and models. In this study issues emerged from the action learning that led to the refinement of the ICP documentation. For example, several presentations focused on the difficulty people had in recognising the stage of dying. Through questioning, people were able to articulate other aspects that they used to make the decision that a person was dying. As a result, modifications were made to the ICP that made it more relevant to nursing home staff. This is explored more in the next section (4.2.2) and then taken further in Chapter 5.

4.1.7 General comments on the benefits of how action learning facilitated the study

Many comments were made about the impact of this process on personal development. Participants' observations on their personal development resonate with objectives identified by Mumford (1996) – valuing input from others, and protected time to think through processes, to step back from the study and see it through another perspective.

"In the group it alerts you to how people react in different ways. I need to take a step back and look at things more broadly is one thing I will take away."

[KC1. NH.C, ALS evaluation: para 16].

The dialectical nature of the process enabled group members to view a situation from multiple perspectives and see alternatives:

"It's made me see that there is more than one answer to most problems. I'm dogmatic but I've started to think around things more."

[KC2. NH.C, ALS evaluation: para.47].

"I think the whole frustration, coming and talking about it...you don't get time at work. When I leave here I feel more relaxed about it...there are folk in the same boat as me and they have sorted it."

[KC1. NH.D, ALS evaluation: para.47].

Some participants identified this approach to learning as different to any other approach they had experienced. Their comments usually referred to the way in which this process challenged their thinking:

"It's powerful. You can't intellectualise it. It's challenging – you are forced to recognise the situation, the way you behave, the way you see life. It's a lot more powerful than any other learning approach."

[KC1. NH.C, ALS evaluation: para.8].

"...you don't get told things, you are made to think yourself and decide which way to take so nobody tells you what to do, you are just enlightened on different ways you can deal with a situation and it is entirely up to you to think about it yourself and decide which way you want to go and which way is the best for you so at the end of the day nobody is telling you what to do ..."

[KC. NH.A, final interview: para.101].

Several participants made comments about the increase in their confidence and self awareness, benefits that are highlighted in other literature advocating this approach to professional development:

"You begin to feel comfortable. It is less formal, although you have guidelines and rules; it is less formal than a lecture. You become more self aware of your actions. I feel my confidence has grown. I find it hard to talk in front of others."

[KC1. NH.D, ALS evaluation: para.19].

In conclusion, the use of action learning to support the key champions to implement the ICP documentation in practice was important for the following reasons. Firstly, it produced, in some instances, a better understanding of the data. An example of this was the constant reference to the difficulty of getting GPs on board with the study. We had evidence of this through interviews with the nurses and the lack of GP attendance at organised meetings. The action learning enabled participants to explore the factors that underpinned this lack of involvement. It was clear that there were many assumptions being made about the lack of involvement and that more work needed to be considered to check out these assumptions and analyse approaches to collaborative working. Resultant actions could potentially be used in an action research study as spin off spirals requiring implementation and further evaluation. The timescale of this study did not allow for full implementation and evaluation of these actions.

Secondly, it provided some reciprocity in the researcher/participant relationship, in that an experience was created to enable the participants to learn formally from the process of being involved in the research. It was clear from the evaluation data about action learning that participants had learnt a great deal from taking part in this process, and that this learning for some at least seemed to be qualitatively different from other types of learning they had experienced in the past.

Finally, it provided the support necessary for participants to play a more active role in the research process. Through the process of action learning, the participants developed more confidence in their role as change agents, and developed more effective communication strategies to enable them to get others on board and present effective arguments based on evidence to influence decision making in this change process.

4.2 FACILITATION THROUGH ‘COLLABORATIVE LEARNING GROUPS’

This section outlines the facilitation that occurred during the collaborative learning group sessions following a death in a nursing home. These sessions fulfilled a number of roles which included:

- allowing people time to critically reflect around the care given to the resident who had died and learn what they might have done differently;
- allowing the opportunity to teach about aspects of end-of-life care as it arose during the groups;
- supporting those involved in caring for a resident who had died;
- reflecting on the process of completing the ICP documentation;
- understanding together how the ICP documentation might be further adapted to the nursing home context.

A key factor of the facilitator’s role was the lengthy experience as a nurse specialist in palliative care. This enabled the sessions to be informal and yet fluent around whatever issue was raised. Many subjects were covered (see Table 4.1) and sometimes subjects were repeated on more than one occasion. A planned meeting each month with the nurse manager immediately prior to the collaborative learning group in each nursing home gave the facilitator the opportunity to keep in touch with the nurse manager regarding the study and in some cases encouraged them to attend.

4.2.1 Using the collaborative learning group to enhance end-of-life care

It was important to create an environment within the collaborative learning groups that was facilitative rather than threatening. Staff, both nurses and care assistants, who had been involved with the resident who had died were particularly encouraged to attend. Each session started with everyone being given a photocopy of the recently used ICP documentation that had been ‘corrected’ by the CNS/researcher. Staff were then encouraged to talk about the resident who had died, how long the resident had been in the nursing home and their feelings about the care given in the last days of life. Time was given to

Table 4.1: Topics covered during the collaborative learning groups

Nursing Home	Number of collaborative learning groups	Aspects of teaching covered during the collaborative learning groups as well as requested topics
NH.A	4 + advice when resident on ICP	Mouthcare, 'prn' medication, anxiolytics, opioid toxicity, appropriate routes of medication, spiritual issues/anguish, process of dying, swallowing reflex in last days of life, pneumonia/the 'old man's friend', use of hyoscine for rattly chest, talking about dying, 'being with', unfinished business
NH.B	5 + clinical advice	Syringe drivers, dehydration in older people, 'prn' medication, appropriate routes of medication in last days, agitation, opiates and breathlessness, unfinished business, process of dying, pain assessment and DOLOPLUS tool (Lefebvre-Chapiro (2001)
NH.C	6 + clinical advice when resident on ICP	Pain assessment and DOLOPLUS tool, euthanasia, fluids in last days of life, swallowing reflex, recognising dying, changing role of NHs, spiritual needs, use of hyoscine for rattly chest, communication with family re dying process, use of anxiolytics, insight of dying resident, pneumonia/the 'old man's friend'.
NH.D	3 + clinical advice when resident on ICP	Mouthcare, use of hyoscine for rattly chest, talking about dying, 'prn' medication, dying itself is not painful, spiritual care, unfinished business, analgesics, swallowing reflex in last days, communicating with families over the dying process, premonition of dying by resident
NH.E	6 + clinical advice when resident on ICP	Unfinished business with families, pain assessment, syringe drivers, analgesics, nausea & vomiting, swallowing reflex in last days of life, spiritual care, communicating with families over dying process, 'prn' medication, insight of dying resident, rattly chest, agitation, communicating with GPs
NH.F	3 (one of which included GPs from the practice)	Talking about dying, anxiolytics, process of dying/relevant signs, diagnosing dying, pain management, 'prn' medication, unfinished business, rattly chest, pneumonia/the 'old man's friend',
NH.G	4 + clinical advice	Pain assessment and DOLOPLUS tool, pain management, mouthcare, swallowing reflex in last days, talking about dying with families, teamwork, 'prn' medication, nurses' responsibility in care of dying
NH.H	3 + clinical advice when resident on ICP	Pain, talking about dying, use of hyoscine for rattly chest, communicating with families about dying, swallowing in last days of life, use of anxiolytics.

examine the ICP documentation that had been completed for the particular resident. During this time, opportunity was given to pick up on different subjects as the situation led. At the end of each session there was a recap of what staff had learnt personally from the session. During the session detailed notes were recorded by the evaluator, which were then typed up and sent back as a tool for learning to those who had attended.

The various topics that were discussed during the groups arose not only from staff recognizing their own difficulties/gaps in knowledge, but also from the 'corrected' ICP documents that had been analysed by the CNS/researcher prior to the session. Staff appreciated the in-depth discussion within each session about end-of-life care and decision making. Many staff had not considered how 'old people' die. One or two staff spoke about the excessive use of antibiotics for a pneumonia, but mostly staff had not heard of the old adage that 'pneumonia is the old man's friend'. On occasions staff spontaneously talked about how a resident had mentioned 'they were dying'. Time was given to explore 'how' to respond to such a question whether it was a care assistant or a trained nurse and how this increased their confidence to change their own practice.

"Before when a resident said to me they were dying I said 'don't talk rubbish'...after the feedback session I know now to put it [throw the question] back to them... I feel more confident now...."

[CA. NH.D, final evaluation: para.82]

Occasionally staff spoke about some families and relatives as being 'difficult'. The reason behind these so-called 'difficulties' was explored and how honest information about a resident's general deterioration was so important to relieve anxieties. Gradually staff became less frightened to talk about dying and not to be afraid to open up conversations with families. They learnt about the process of dying – that death just didn't 'happen'. By understanding what to observe, staff were able to explain what was happening to other carers and even to a resident's family. Some staff also asked for particular teaching sessions on 'the use of syringe drivers' or 'pain assessment tools' over and above the collaborative learning groups.

Prior to attending the collaborative learning groups, many nurses and even some nurse managers had no prior knowledge of drugs used to control symptoms such as agitation and chest secretions that commonly occur at the end-of-life (Long 1996).

"Most of the circumstances I worked in were a psychiatric setting, physical things came second, psychiatric symptoms were looked at first and as long as they were OK nothing else was thought about. So when we were doing the ICP and we came on to pain control and all these drugs were being mentioned - I didn't know any of them."

[KC2. NH.D, final interview: para.61]

Other staff and some GPs thought that the only drug necessary for older people at the end-of-life was an opiate. Teaching about these drugs in the collaborative learning groups was very important. On the few occasions when GPs attended such a group they appreciated updating their knowledge about various medications. It was the process of using these sessions, along with recapping on the ICP documentation that helped staff feel they knew more about palliative care than before the study. Staff really responded to this way of learning.

The collaborative learning groups were not 'gloomy' despite the discussions being around death and dying. Often there was plenty of good humour within the groups. Care assistants candidly reported that they wanted to be told if they were doing things wrong: "if you don't get told you don't know" [CA. NH.D, final evaluation: para.157]. All the carers and nurses who came to the groups felt that they had been helped to learn a lot, even though at times the sessions might have appeared challenging.

"It's only for benefit – the feedback's been great because you wouldn't have known how you were doing ... but if you have the feedback then you know 'well, we shouldn't have done this, and we could have done that'."

[SN2, NH.A, final evaluation: para.249]

"Constructive criticism on how you had filled in the [ICP documentation] which was good to help us for the next time – the 'A' and the 'V' and what not."

[CA. NH.C, final evaluation: para.182]

Trying to make learning interesting, discussing together and creating the right atmosphere was important. One group even found that the more discursive style had 'rubbed off' on their daily 'handovers'.

"I think at report times too we use those times to recap things - what people have said and things that the family have said and talked about [and] how we respond to those things - which we didn't do before."

[SN. NH.C, final evaluation: para.150]

By using the ICP documentation, staff were encouraged to make their actions towards holistic care of both the resident and the family more deliberate. To begin with the goals around 'unfinished business' and 'spiritual care' were all quite new aspects of end-of-life care for staff and provoked considerable discussion. The documentation encouraged staff to consider these goals and adopt a greater openness on a number of issues.

4.2.2 What staff thought about the 'Collaborative Learning Groups'

The collaborative learning groups were built into the study as a way of critically reviewing how the death of a resident had been, and what issues had arisen with completing the ICP documentation. In six out of eight final evaluation meetings, staff specifically spoke about how useful the collaborative learning groups had been as a way of learning more about end-of-life care and the use of the ICP documentation.

There was a sense that through the groups staff were 'tightening up' their care of residents who were dying; a sense that the groups helped staff to think more about what they were actually doing. An important first step around any improvement in care is for staff to learn to reflect on care given (Rolfe et al. 2001).

"The value of reflection as well...it's definitely been the ICP that has showed me how important and how useful it is...I was just trying to think if it was other parts of what I am doing as well but probably no, the ICP has showed me how important it is for the carers as well to have that reinforcement of what they are doing."

[KC1. NH.C, interview: para.82]

"I think they are maybe just more aware of 'why' they're doing things and what to do about it."

[KC. NH.B, interview: para.58]

Staff who came to the groups wanted to give good care and to learn how they might do things better. Staff did not appear to feel exposed if they had not done something; instead, the groups were facilitated in a way that made them feel they wanted to learn.

"When you know you are doing it right you feel good about it..."

"When you're not doing it right then you learn..."

"It was good to get the feedback about how you were doing it...you'd rather somebody tell you."

[CAs2/3. NH.D, final evaluation: para.256-264]

The opportunity to be more objective about the whole situation in context with the staff around at the time of the death was important. Even if there had been a frank, open discussion about a difficult issue staff still returned for more.

"I think it's the [collaborative learning groups] that we have, each time we go over documentation that has been used, and sometimes these sessions are challenging in that they make you think about how you performed on that pathway and how you can do it better next time.."

[KC. NH.C, final evaluation: para.180]

It wasn't just the care assistants who found the collaborative learning groups challenging. There was learning for everyone: care assistants, trained nurses and for GPs, when they were able to attend. It was important that the different staff in the nursing home were not fragmented – all of us learnt together – the researchers learnt about a differing dying trajectory.

The groups were as useful for teaching about end-of-life care as they were with reinforcing the use of the ICP documentation

"Its only for benefit...the feedback's been great because you wouldn't have known how you were doing, if you were dealing with one person who was dying and then after the death you gave the stuff to (key champion) and she gave it to [CNS/researcher] ...but if you have the feedback then you know well, we shouldn't have done this, and we could have done that..."

[SN. NH.A, final evaluation: para.249]

Over half of the nursing homes had plans to continue the collaborative learning groups.

"Continuing to have the reflective session after each one is complete. I think that is critical to people's on going learning and motivation"

[SN. NH.C, final evaluation: para.262]

However, some nursing homes may not be confident enough to continue the groups on their own.

As a result of attending the collaborative learning groups, one nurse manager admitted finding it difficult to 'look out' for staff when a resident was dying. She acknowledged that often it wasn't until a nurse or a carer was 'falling apart' that they noticed that something was wrong.

"...I can't say that we've always been awfully good at that, supporting staff. When individuals don't cope with it we tend to support them very well but we don't support the one who doesn't sort of fall apart and break into tears. You know it's the one who still has to sort of internalise it somehow, we haven't been so good at that."

[NHM. NH.H, interview: para.44]

This reinforces the idea that staff need a formal group in which to be able to share their feelings before 'they fall apart'. Many staff have a very close relationship with the resident after months of caring (Irvine 2000). The collaborative learning groups were a good way not only to review the care given and review the ICP documentation, but gave a planned and official time where staff shared how they were feeling following a resident's death.

4.3 FACILITATION THROUGH THE ROLE OF THE CLINICAL NURSE SPECIALIST/RESEARCHER ROLE

The CNS/researcher provided the initial education relating to the use of the ICP documentation to enhance the quality of end-of-life care to the key champions at the commencement of the study. After this, the key champions arranged for all staff in their own nursing homes to attend the introductory teaching about the documentation. A case scenario (Appendix 8) was used at all these initial sessions to encourage staff to complete a pretend ICP documentation which they could then take away. A 'mock' ICP was then put in the ICP ward file for reference.

The CNS/researcher also facilitated the monthly collaborative learning groups, co-facilitated the action learning sets, attended monthly meetings with the nursing home managers, met with GPs to inform them about the study, and provided ongoing telephone support/visits to the nursing homes to advise on end-of-life care issues. All the nursing homes identified this support as essential.

Several people said that having an expert coming from outside was very helpful, both in terms of an 'outsider' not being involved in the politics of the organisation, and in terms of reviewing the ICP documentation objectively.

The nursing home staff and GPs appreciated the expertise of the CNS/researcher when she came out to help them with residents who had symptoms which were difficult to control, complex 'unfinished business' within families, or getting someone started on an ICP. The CNS/researcher provided support in these situations to enable the staff to do it themselves rather than doing it for them.

Having the back up of a specialist in palliative care was also important for the nursing homes in getting the GPs familiar with the ICP documentation, particularly at the beginning regarding various drugs used in the last days of life.

"...If I just think about pain control on its own how we advanced in that. Being able to have access to (CNS)... it was very nice having the backing, calling the doctor and saying a nurse pain specialist is giving me a bit of help and advice here...so I think that went fantastically for us..."

[KC. NH.G, final evaluation: para.59].

Staff felt that GPs were receptive about the ICP documentation when they had heard about it from an expert in palliative care. In situations where a meeting had been successfully arranged with GPs in order to get their support prior to the study, when a resident was dying and the ICP documentation needed to be commenced, the process went smoothly. However, where GPs did not respond to the invitation to hear about the study, despite a letter written by the nurse manager and followed up by the CNS/researcher, there was more tension.

Nursing home staff are isolated not only from palliative care education but also from day-to-day support and advice (Froggatt 2001a; Katz et al. 2001). This study highlighted the same issues. A CNS/researcher being available as an integral part of the study was really appreciated by staff facing more complex and difficult end-of-life situations.

4.4 SUMMARY:

This chapter has looked at the way facilitation was a key aspect of the study in the process of implementing the ICP documentation and developing knowledge about end-of-life care in the study nursing homes. The 'high' level of facilitation employed in this study was an important factor to counter balance some of the barriers inherent in the nursing home contexts. The appointment of key champions as 'insiders' (Titchen & Binnie 1993) and then supporting them through the action learning sets was implicit in the facilitation design. The 'collaborative learning groups' used to reflect on end-of-life care alongside the use of the ICP documentation facilitated the immediate knowledge around end-of-life care for all staff *within* the nursing homes alongside clinical advice.

Chapter 5

The impact of the project on end-of-life care

This chapter considers the impact the study had on end-of-life care in the eight nursing homes involved. Firstly, there is an examination of the themes that emerged from the analysis of data from the final evaluation groups in each nursing home and the final interviews with key champions. Secondly, the chapter details changes in the documenting and prescribing around end-of-life care as a result of the study by comparing the base review with care recorded using the ICP. In the third section there is an analysis of the final questionnaire sent to all staff in order to capture staff perceptions on how the study directly influenced the day to day practice of care during the last days of a resident's life. Finally, there is some evidence for the potential sustainability of the changes made to end-of-life care in the study nursing homes.

5.1 DYING BECOMING 'LESS PERIPHERAL' TO NURSING HOME CARE

Throughout the study there was a crystallisation (Borkan 1999) of an overarching pattern that the care of dying residents was becoming more central to nursing home work and less on the periphery.

"...it's been a really successful thing in bringing death and dying to the fore and not to be so frightened of it"

[SN3. NH.H, final evaluation: para.63]

Out of 215 nodes and fourteen main categories highlighted during the study, five main themes emerge from the data that contributed to this shift in making dying less peripheral to nursing home care:

- A greater 'openness' around death and dying
- Recognising dying and taking responsibility
- Better 'teamwork'
- Critically using knowledge about the dying process to influence practice
- More meaningful communication

5.1.1 A greater 'openness' around death and dying

In nursing home care, staff's discomfort with death and dying has been reported (Forbes 2001). During the study, the existing covert culture surrounding death and dying in the majority of nursing homes prior to the study gradually dissipated as key champions and other staff became more confident to open up communication around death and dying. By the end of the study dying was less of a secret event in the nursing home.

".. it's not 'hushed hushed' discussion now - it is more open - the fact that now this personthey are on the ICP.....OK - we're expecting this person is going to die - quite imminent. It is not as 'hushed, hushed' now - you are talking about it."

[KC1/2. NH.D, final interview: para.65]

Because the ICP documentation was in the resident's room, carers were no longer in any doubt that the resident was dying. Staff became more open to talk about dying while it occurred. A resident who was dying became an important focus rather than someone 'slipping away' unnoticed.

"It has definitely changed a lot...I am aware of any death that is happening in the home and it's not just me who knows, everybody else knows and everybody respects that ...so it is something that never used to be there ...before people on a different floor would find out two weeks or maybe three weeks after somebody has died [now] it's something that everybody knows, not only the carers or the nurses but the domestics are well aware..."

[KC1. NH.A, final interview: para.135]

Over the months of the study a number of changes in people's attitudes towards death and dying were observed. Staff were becoming more aware of the real frailty of their residents. Nursing home teams were openly acknowledging that a resident might be dying, and there was a valuing of each other's opinions.

"Probably the biggest change that I have seen ...we all talk about it together. And carers are involved in decisions about whether or not we think people are dying...."

[KC2. NH.C, final interview: para.179]

In this increasing 'openness' around death and dying, there was an opportunity for some carers to express their fears and/or superstitions about death and dying. With this came a greater understanding about dying and its process.

"It's understanding the dying process. What you don't understand you're frightened of."

[CA.NH.G, final evaluation: para.72]

Many of the staff had vivid experiences of deaths within their own families that they wanted to explore. The collaborative learning groups became a natural focus for this sharing. Moss et al. (2003) describe similar findings in their study. They found that the sharing helped bring meaning to both the carer's personal grief and the grief surrounding the deaths of residents in the home. Being able to talk about death and dying enabled fears to be lessened.

In one of the nursing homes where the study had a considerable impact, a greater openness around death and dying was being introduced within the nursing home community as a whole.

"...Yes, and instead of shutting people away - especially in the dementia unit, we used to put them in the sitting room with somebody standing outside the glass door that they couldn't leave - I don't do that at all now.... we prepare them.. and say, 'so and so died and they're going away shortly' ..."

[KC1/2. NH.E, final interview: para.127-133]

Inadequate communication about dying with nursing home residents is not uncommon (Kayser-Jones 2002). The amount of openness that developed was not something that came easily to a majority of the nurses involved in the study. However, a couple of nurses spontaneously reported that when speaking to a relatives they had actually found themselves using the word 'dying' instead of 'more poorly' or another such euphemism.

5.1.2 Recognising dying and taking responsibility

The nurse in a nursing home has a very important role in organising the care for residents who are dying. Although Brazil et al. (2004) talk about the importance of recognising death as a significant event in long term facilities, it is important to stress that the actual dying process is a vital part of this. Often the important role of the nurse in this is not realised. This study highlighted how such a role became more apparent.

*"I suppose [the ICP documentation] makes you realise how important a role you've got in palliative care...it's such an important thing."
[SN1. NH.H, final evaluation: para.93]*

Prior to the study there was a lack of confidence in some of the nurse's ability to take responsibility to initiate what was necessary for their residents' end-of-life care – whether this was talking to relatives, ensuring that there were drugs for distressing symptoms, or informing other staff in the nursing home that a resident was now dying. Often this was because it was seen as the GP's position to diagnose dying, even though in the majority of situations it was the nurse and indeed the carers who knew the resident and the family the best.

*"I think before it was more or less the doctors who decided. Now I feel the carers are as much involved."
[KC1. NH.E, final evaluation: para.49]*

What was important about the ICP documentation was that it encouraged a joint decision to be made around the diagnosis of dying. The nurses' important part, along with the ward team and resident/family, in initiating that process was being recognised. It was encouraging to see nurses more accountable in this important area of care and the pride of their nursing home managers.

*"... We are taking a bit more responsibility....I think it has raised the standard of care of the dying."
[NHM. NH.D, final evaluation: para.53]*

*"I think the trained staff...there is this real ability for them to be more in control.....they feel that their professional opinions are being much more respected."
[NHM. NH.E, interview: para.79]*

McCue (1995) explores the importance of making a diagnosis of dying so that dying in old age is highlighted as an inevitable process that is independent of underlying disease/s. The ICP documentation encouraged such a diagnosis. Without this it 'deprives the dying of their autonomy, leading to questions such as "Whose death is this?" (McCue 1995:1041).

Knowing when to start the ICP documentation was an issue for the majority of nursing homes at the commencement of the study. Key champions were telling us that the deaths had happened too quickly and that there wasn't the time to start the ICP documentation. Katz et al. (2003) encourage the notion of a dying trajectory over a longer period of time in the case of elderly frail people. Gradually staff realised that perhaps it was their lack of experience at picking up on the clues that someone was dying which meant that they had not started an ICP at the appropriate time. As staff took more responsibility for recognising dying by reviewing the bigger picture of deterioration, the ICP documentation was more easily implemented.

*"If you think about a couple of cases of people who have become very ill and died, before the ICP, 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."
[CA3.NH.A.final evaluation: para.237]*

The ICP documentation was enabling a greater consensus around diagnosing dying and the aims of care for a resident and their family. It was as though the ICP documentation gave staff 'permission' for the focus to change and for dying to be diagnosed. In the nursing homes where the ICP documentation was eagerly welcomed and adopted by nurses, carers, relatives, and GPs, there was a forum in which a diagnosis of dying could be made so that the dying phase was appropriately managed and symptoms controlled.

Staff admitted that changing from a reactive position to being more proactive in recognising dying was one of the biggest changes for their nursing home. Others described their previous lack of preparedness like being on the back foot:

"I feel better equipped to anticipate problems whereas the contrast before the pathway [ICP]...we were always on the back foot - the problems would happen and then we would try and deal with them and often there was a time lapse...getting drugs to deal with it whereas now everything is anticipated and you are prepared and so therefore you deliver a far better service."

[KC1. NH.C, final evaluation: para.96]

By recognising dying, both nurses and carers were more able to be involved in the actual dying process itself.

"I think, you know before [when] somebody died, you were waiting for them to die but now you are going to do something about them when they are dying..."

[S2. NH.A, final evaluation: para.98]

The ICP documentation enabled them to 'mark' the process of dying and feel more in control of the whole process.

"... we are looking at individuals at a different stage now and we're saying 'is it time' and we are evaluating that whereas before the slide would probably have gone on and then suddenly we would realise that death was imminent, you know somebody was taking to their bed, the usual things that happen whereas I think now we are much more proactive ..."

[NHM, NH.H, final evaluation: para.74]

" I think we are becoming more involved with the actual act of dying, you know people aren't just going, oh we'll turn then four hourly, we'll do this and we'll do that you know like you did for years and years and years. It's sort of approaching [it] in a much more sensitive way I think, you know you are thinking about, not just about...I suppose the family and the relatives but you're thinking about everybody else in the home."

[SN2. NH.A, final evaluation: para.54]

Staff now not only acknowledged what was happening but were more confident in explaining this process to relatives.

"I asked her how would we know and they did explain what would happen about the change in the breathing and things like that, sister [the KC] explained all that ...what we could expect to see..."

[Relative 3. NH.C,para.70]

Because dying was being made more 'official' and carers were being included in the recording of care in the ICP documentation, carers appeared eager to take an increasing part in the care.

"I think from the carers' point of view that we are more involved with recognising different stages in the dying...and work together...much, much more aware of the whole dying process. And I feel more involved, ...you feel within yourself that you can cope better with what's happening and with the people around you. It makes it all a lot easier ..."

[CA6. NH.B, final evaluation: para.82]

Carers talked as though the care they now gave when a resident was dying was 'more special'. It was as though there was more effort being put into the care. Staff actually talked about spending longer in a resident's room when they were dying.

"Well if you've got somebody on an ICP on your floor then they are sort of your main person for the day so you keep checking on them all the time and I think you probably spend more time with these people now than we used to."

[CA3. NH.A, final evaluation: para.172]

Some would offer to stay on and sit with a resident at the end of a shift in order that they weren't alone until the night staff could take over. However, there were carers who because of an added responsibility felt more deeply the emotional burden of looking after someone who was dying.

"I think the fact is, you know when somebody is on an ICP, you know they are going to die and when you're sitting with them it can get a bit difficult when you start thinking too much, I find that quite difficult."

[CA3. NH.A, final evaluation: para.210]

Many staff were very close to the residents because of the caring over several months/years. Nursing home managers and owners need to be aware of the burden many of their staff take on during the dying phase of residents in the home, and ensure that appropriate support is provided.

5.1.3 Improving 'teamwork' – both inside and outside the NH

The importance of good interdisciplinary teamwork to enhance quality of end-of-life care in nursing homes is vital for residents to receive the care they need (Hanson et al. 2002). At all the final evaluation sessions in each nursing home participants talked about how the study had improved teamwork when a resident was dying.

"It's pulled all the factions of the team together in a lot of ways and certainly when we do look after someone on the pathway it is a really good team effort."

[KC2. NH.C, final interview: para.32]

"...the pathway it draws everybody together, everybody is going in the same direction, everybody is doing the right thing and it makes a huge difference...."

[SN. NH.C, final evaluation: para.47-51]

There was a greater respect for each other's roles. In the past, some of the carers had felt 'left out' of the caring in the last few days of a resident's life, even though they had cared for the resident for many months, and often a couple of years. The ICP documentation however made them more involved together. The ICP provided a less hierarchical structure and facilitated a flatter, more collaborative arrangement which helped carers to feel a more 'included' member of the team (Wicke et al. 2004).

"And it's nice that that comes back to us that's what I've been trying to say in a roundabout way it's nice to know that comes back to us.... Instead of just feeling like the person who is washing and cleaning them...and not getting a say - now we are getting a say."
[CA, NH.G; final evaluation: para.290-296]

By completing the ICP documentation alongside the nurse in the resident's room, carers felt their role was more valued. It gave them continuity especially if they had been away on days off; it enabled them to look back and see what had been going on, and thereby aided better communication. It helped to improve carer's confidence when a resident was dying.

"...you felt as if you were more of a team working with it. You knew what was happening because it was all wrote down...You knew what you were trying to achieve."
[CA2. NH.D, final evaluation: para.27-33]

".. well definitely better communication because it's all in one place ...the pathway is in the room, it's just a lot more compact and it's there and its easier for everybody.."
[CA4. NH.C, final evaluation: para.78].

In all of the final evaluations nurses and carers talked about all pulling in the same direction with the same aims for the same goals "because we're all singing from the same hymnbook, we've got the ICP guidelines which encompasses all." [CA2. NH.A, final evaluation: para.4].

Carers really appreciated being involved with the study. They saw it as a real opportunity to learn about death and dying:

"...when people are dying, the things to look for, you know what I mean, it's not just going over your head, a lot of the time it is whereas, there's signs there and they're telling you exactly what's happening as it's going along, whereas a lot of the times you just didn't get told that..."
[CA2/3. NH.F. final evaluation: para.45-49]

Nurses mentioned that because carers were being given responsibility for filling in the ICP documentation, it made some of the more senior carers more responsive to working with other documentation in the nursing home.

"..They've started taking more interest in the rest of the notes, whereas in the past, they didn't take any notice they wouldn't even open them..... they weren't encouraged to, and more and more they are looking at things and writing things in and you know, reading bits, yeah definitively, it's made a difference. I think it's partly because they now realise that they really are part of the team and you know, that is part of their role."
[KC1/2. NH.C, final interview: para.206-215]

Although much of the emphasis on improved teamwork within the nursing homes was amongst carers and nurses, there were signs that collaborating with GPs had also improved. At the beginning of the study it was an uphill struggle for many of the trained staff to get their GPs involved in the study, and

to prescribe for end-of-life care. This lack of GP/physician involvement is not uncommon (Forbes 2001; Hanson et al. 2002) and has already been identified by one matron of a nursing home as being a major hurdle when she was trying to introduce the Liverpool Care Pathway (Ellershaw & Wilkinson 2003). GPs play a vital part in the provision of appropriate symptom control at the end-of-life even though the nurse is likely to be the most important professional carer (Kurti & O'Dowd 1995; Hall et al. 2002). Often the ICP documentation was filled in as 'nursing' documentation despite indepth teaching on the importance of 'integrated care' as part of the study. By the end of the study, however, key champions in five of the nursing homes reported an improvement in their relationship with GPs.

" It's also done a lot in our relationships with the GPs as well, it's given us, well me, more confidence in asking GPs for what I think people need and given me the knowledge to sort of argue the point as well..... I think because we are more confident with what we need as well, they are more inclined to listen."

[KC1. NH.C, final evaluation: para.39]

These GPs genuinely appeared more ready to listen to the nurses as the study progressed and the nurses became more confident in what they were requesting. A reflection written by one of the key champions at the end of the study was very encouraging:

'I felt there was a relationship built up between the GP and myself because I was able to ask questions at a level I felt accepted. And he was willing to answer and also listen to my opinion. I felt it was a better working relationship and collaboration in care. He made me feel valued – my opinions were respected. Time was not a factor at that moment, he took his time and went through all the documentation and we discussed issues as we went along. I felt this incident boosted my confidence in the doctor-nurse relationship.'

[KC1. NH.A.]

Nurses were also more 'up front' about what they needed. Many reported that they hadn't done this before. The ICP documentation helped the nurses to be more organised. This in turn helped them to be more confident when speaking to their GP colleagues.

"Communicating better with the doctors and being a bit up front about what we might need before we need it. We didn't do that before.."

[NHM.NH.D, final evaluation: para.106]

Nursing home managers felt that some of the GPs were happier for nurses to take more of a lead. There was a sense that GPs themselves were becoming more in tune and more sympathetic to prescribe different medications that a resident might need at the end-of-life.

5.1.4 Critically using new knowledge about the dying process to influence practice

The criteria to 'diagnose dying'⁶ used as a guide to commence the ICP documentation, could be potentially ambiguous within the nursing home context. There were a number of reasons for this; some that were inherent in the context and some that were due to the prolonged dying trajectory in older people. Being 'bed-bound' and/or 'confused' and/or 'difficulty taking oral medication' doesn't necessarily mean an older person with advanced dementia is dying. It was important for staff to think critically about the overall quality of life and see this within a dwindling dying trajectory (Lynn & Adamson 2003). This genuinely needed the appropriate support of a GP. However, it also required the confidence of the nurse and the intuition of carers/relatives to speak about a problem, such as a further

⁶ Ellershaw & Wilkinson (2003) use 4 criteria to diagnose dying along with the multidisciplinary team agreeing that a person is dying (see Appendix 15)

pneumonia within the context of the resident's quality of life, rather than an isolated symptom on its own. Many phrases were heard such as "he's just not right", 'the light had gone out of his eyes' or 'he's telling us he's done', which staff gradually appreciated as being important criteria specific to the context that complemented the other more formal criteria for diagnosing dying.

If this critical thinking did not occur then there was a danger that an ICP documentation might 'condemn' a resident inappropriately. A situation within one of the nursing homes highlighted the importance that the ICP documentation should only be started after 'open' communication with a GP who knows the resident, and/or a senior nurse who has cared for the resident for many months, and, where at all possible, with the family present.

An extract from fieldnotes [NH.E, para.78]

'67 year old gentleman suffering from MS in one of the project nursing homes – seen by a locum GP at the request of a 'bank nurse' – resident had suddenly deteriorated. Resident had been in the NH for a number of years and had clearly been deteriorating slowly but family shocked to be given the diagnosis of a CVA by the GP and that the resident was now dying. Both sister and senior staff nurse were not around. Ward being covered by bank nurse and 'floating' nurse. Floating nurse asked for help from a sister from another unit re implementing the ICP for the last days of life. Resident's wife initially very upset to think that her husband was now dying. Son was not accepting the situation and asked for a second opinion. 24hours later following a second opinion the resident was sitting up in bed. The diagnosis of CVA was wrong and the resident had had a severe UTI to which he had been prone.'

The complexity of end-of-life decision making within the nursing home context should not be denied. However, when doctors and nurses who knew the resident made a considered, unhurried decision along with close family/friends commencing the documentation was not a problem.

Using the ICP documentation made it more likely that problems such as pain, agitation, and 'rattly chest', which were being monitored every 4 hours, would get reported.

".....if one of the carers comes and says he sounds a bit funny, you know you won't say 'Well, they always sound a bit funny when they are dying'. You say, 'Well, OK, we'll go and have a look at them.' You know so you're getting all the information from everybody and you're acting on what you are getting...I think it's been really good."

[SN. NH.A, final evaluation: para.174]

There was a considerable amount of knowledge that nurses said they had learnt about the control of symptoms at the end-of-life. For example, many of the nurses – like their GPs – did not realise the strength of opiate in a Fentanyl patch [see 5.2.2 for further discussion re symptom issues]. Sometimes there was frustration that a GP appeared to know less about palliative care medication than the nurses' increasing knowledge. However, because the ICP documentation folder included official local palliative care guidelines on symptom control (Lothian Health Palliative Care Guidelines 2001), this gave GPs greater confidence in agreeing with the nurses what to prescribe.

"... [the nurses] feel that their professional opinions are being much more respected. ...we know we've got this in place, we know what we might need and we can decide the minute that we see that coming, this has gone to the next stage and they are in control of that. I think that collectively they feel that it's a much less harrowing experience for the residents, their families and the staff."

[NHM. NH.E, interview: para.79]

In-depth knowledge about anxiolytics and medication to control noisy secretions at the end-of-life were unknown to the majority of staff at the beginning of the study. Agitation or terminal delirium is a particular problem with nursing home residents dying with end stage dementia (Hall et al. 2002). By the end of the study, not only was every key champion familiar with the different drugs, but other nurses and even carers were much more informed.

"Managing pain and knowing the drugs that are used for drying up secretions I've learnt a lot about that. And the changes that take place..."

[SN. NH.D, final evaluation: para.7]

"When you hear a rattly chest now you are immediately thinking hyoscine... whereas before you wouldn't."

[CA2. NH.A, final evaluation: para.301]

In a couple of the nursing homes, GPs 'held back' on prescribing 'prn' medication with the excuse that they would willingly prescribe a medication if and when the resident required it. This was in direct conflict with one of the main reasons behind the ICP documentation framework where prescribing medication in anticipation of agitation, respiratory secretions and pain in the last days of life is encouraged. Perseverance in asking the resident's GP to prescribe the necessary end-of-life medication in advance did win through in the majority of nursing homes. Where the GP was willing to work in a multi-disciplinary context and respect the important role of the nurse, their judgement regarding symptom control and their knowledge of the resident, it worked well.

"...he certainly doesn't hold back with prescribing now which is better...we used to have to fight with him before to get a good regime but not now...especially 'prn' medication we get almost routinely, whereas before you couldn't get it...until they were in agony."

[SN7.NH.E, final evaluation: para.105-107]

It would be wrong to convey that every resident on an ICP was now getting all drugs for end-of-life care written up. There were still problems if a nurse was not specific about what they wanted; for example, oral medication such as oral morphine would be prescribed rather than s/c diamorphine. The oral morphine would be used for one dose, but then the s/c route would need to be used, necessitating a further interruption in the GP's busy schedule, and a further trip to the chemist. Nonetheless, it was an enormous learning curve for key champions, nurses and GPs alike - a challenge that some took on with a real sense of achievement.

"I think they've learned that if they give us what we want, things go more smoothly...we know what we are talking about, we don't know everything about it yet but we are getting better at it as we get more confident."

[KC2. NH.C, final evaluation: para.170]

"Personally I've learnt a lot from [being involved with] the ICP [study]...why are we doing this, it makes me question more."

[KC1. NH.E, final evaluation: para.94]

Being more aware of what was happening and having more knowledge about the dying process had a 'freeing' effect for many of the nurses and key champions. They were empowered in their role as an important professional organising end-of-life care for their residents.

5.1.5 Deeper more meaningful communication

With a greater openness and more knowledge about the process of dying, deeper and more meaningful conversations opened up with relatives and even with residents themselves. It was encouraging to witness that it was not just the key champions who were feeling more confident but also the other staff in the nursing home. Prior to the study staff had felt scared to say anything if a resident mentioned death or dying. Now more attention was made to address concerns, and staff were more prepared to allow a resident to speak meaningfully about their life and death, if that was what they wanted to do.

"..... not sort of brushing it off with a throw away comment...she'll be fine tomorrow, but actually taking the time to sit and say 'well what is it that is making you feel that way?' There's a lot more of that stuff that is happening, an awful lot more...."

[KC1, NH.C. Final interview: para.177-179]

Forbes (2001) relates how in her study residents were comfortable talking about death but staff hadn't known how to react. These results were mirrored in our study prior to facilitating the implementation of the ICP. However, gradually staff realised the importance of acknowledging what residents were trying to say to them. As staff related stories of situations during the collaborative learning groups about residents voicing the fact that they were dying, we also learnt that many residents appeared to choose when they died.

"...[resident] told me that a couple of days before he went, you know he actually says to me, 'I'm done - I am tired - it's time to go.'

[CA. NH.G, final evaluation: para.386-387]

Staff were learning the importance of allowing residents to make choices even around end-of-life care. Singer et al. (1999) reports this 'sense of control' as one of five dimensions that older people dying in a long term care facility said contributed to their quality end-of-life care.

Staff were now also more willing to involve families in the dying process; helping them to understand what was happening stage by stage.

"...we were not inviting the relatives into it as much as we do now. And I feel that we are actually, we feel comfortable talking to the relatives about impending death, and they are quite comfortable as well to ask us anything if they need to ask anything, so I feel there is, we are actually closer with the staff and the relatives, sort of drawn close together because of this openness and preparation for the forthcoming death."

[KC.NH.A, final evaluation: para.25.]

Relatives picked up the ICP documentation that was kept in the room and specifically commented on the care that was going into the last days of life.

"... the daughter]was amazed, she read [the ICP document] and said I'm amazed at how much care and planning is put into this - that was one of the comments she made."

[KC1. NH.E, final evaluation: para.118]

The goals in the ICP documentation actively promote 'holistic care' of the resident and their family. One staff nurse was surprised at the work that they were able to do with a family to unravel the 'unfinished business' before the mother died. It was an emotional drain for the staff nurse and sister involved, but one in which they achieved so much both for the family and for themselves.

Before the study there had been little in-depth attention to the 'spiritual' needs of residents even prior to the dying process and, although more attention still needs to be given to this whole area of care, staff were beginning to grasp its importance. Knowing about spiritual need, picking up on it and enquiring about it with residents/families was quite alien to a majority of staff. The goal in the ICP documentation around spiritual care was broadened to include the importance of favourite music, the reading of poetry or relevant spiritual texts as appropriate, and being close while a resident was dying (see Appendix 15). The ICP therefore prompted staff to consider these things when caring for residents. Staff now paid more attention to the religious needs of residents for example who used to go to church or had a regular visit from a priest. Relatives were often extremely responsive when staff enquired about whether they would like a priest to come and visit during the last few days. One nurse recounted such a situation:

'The man was not a practising Catholic but because the goal around 'spiritual care' was there in the ICP document she asked the family if he would want a priest. The family decided that because their father was brought up as a Polish Catholic then, even though he wasn't practising and did not have his own priest, that it would be nice for him to have the last rites. The home contacted a local priest who came in and visited. The nurse felt it opened up a conversation with the family about the resident and his childhood in Poland. She did not think she would have asked about the last rites if the ICP had not prompted her because he was not practising.'
[NH.C, ICP 3,5 & 6: para.26].

This greater sensitivity and care being given to dying residents and their families was appreciated. In one nursing home, the nursing home manager had pointed out that the content in 'thank you' letters/cards had changed.

"The kind of thank-you's that we have been getting in the last number of months are more detailed. These people seem to have gone to more effort to make specific comments ...comments on the way that the whole team were there for them and the way that the care is coming over is more strongly felt...and the number of people who have not just sent the card or the letter to the unit, they've sent it to me because they want me to know how well these people have done."
[NHM. NH.E, interview: para.83]

Where open communication and decision making around death and dying can be achieved between staff and resident, families and GPs then nursing homes can become a place where the naturalness of dying at the end-of-life is not overly medicalised, and residents are able to feel confident that the dwindling dying trajectory will not be falsely prolonged. Due respect for the 'wholeness of life requires that we do not debase its final stage' (McCue 1995: 1039).

"Accepting that death is a natural process really that, that was one issue for me really, because I think personally to start with I really took death as, I didn't know how to deal with death myself but this has enlightened me, made me accept death as a natural thing and...make the person comfortable in dying"
[KC1. NH.A, final evaluation: para.86-88]

In ignoring this, care at the end-of-life is relegated to the 'bounce back' phenomenon of not recognising dying and hoping that the resident 'won't die on my shift'.

5.2 USING THE ICP DOCUMENTATION

5.2.1 Changes in documenting and prescribing around end-of-life care

During the ICP study forty-one ICPs were completed by the eight nursing homes during the study. Table 5.1 shows that each nursing home used the ICP documentation. Half the nursing homes used the documentation on more than two occasions. The ICP documentation was more often used in nursing homes where a key champion had previously undertaken a 'validated' NES⁷ palliative care course (although NH.A was an exception), where students on the course use reflection to challenge their assumptions and beliefs of end-of-life care.

Table 5.1: Number of ICPs used in the nursing homes

Nursing Home (number of beds)	Number of ICPs used	Number of GP practices	No. of KCs in NH at end of study	Previous 'validated' PC education for KC
NH.A (60 beds)	8	1 (for 50%)	2	No
NH.B (28 beds)	1	multiple	1	No
NH.C (72 beds)	13	1 (for 80%)	2	Yes
NH.D (47 beds)	2	2	2	No
NH.E (114 beds)	8	1 (for 90%)	2	Yes
NH.F (40 beds)	6	1	1	Yes
NH.G (70 beds)	1	multiple	1	No
NH.H (54 beds)	2	multiple	2	No

The other factor that appeared to affect the use of the ICP documentation was where one GP practice gave the majority of the medical cover and therefore had a more in-depth working relationship with staff at the nursing home. Two nursing homes managed to get all their GPs to complete and sign the initial assessments when first starting the ICP documentation denoting real collaboration at the commencement of the study. However, a number of key champions and nurses started using the ICP as nursing documentation in the first instant prior to getting their GP colleagues on board. Thirteen out of the 41 initial assessments just had a nurse's signature.

The ICP documentation was used to record the residents care on average for 4 days prior to death [a range from 12 hours to 9 days]. Three residents 'came off' the ICP documentation because their condition had stabilized but all three later died with the ICP re-instated.

The forty-one ICP documents were compared to the collated LCP base review documents of the thirty case notes examined prior to the implementation of the ICP (see Chapter 2:2.2.3). Out of seventy one case notes (review notes + ICPs) 7% of the residents in the nursing homes died of cancer, with the majority of other deaths occurring from advanced Alzheimer's disease and stroke.

⁷ The NES (NHS Education for Scotland) validated course at the Hospice is the only course specifically addressing the palliative care needs of older people currently in Scotland. There are many specialist palliative care courses addressing the needs of people with cancer but the complexity of pain assessment for people with advanced dementia is just one example of how different the palliative care trajectories are.

In the base review of notes prior to the implementation of the ICP documentation there was some reference in a number of the notes to a resident being an 'expected death' but not that they were actually dying. This 'expected death' policy meant that the nurses could pronounce life extinct and that a GP did not need to visit after the death. It gave a functional prediction that the resident was likely to die at some point, but not necessarily dying at present and gave little anticipation around the importance of the dying process to the resident and relatives.

Prior to the ICP implementation there was evidence that relatives were 'spoken to', and some nursing homes were better than others about documenting whether a relative wanted to be contacted at night. However, there was little documented evidence into inquiring about relatives' needs. There was no documentation about the spiritual needs in the base review.

Results that contrasted most starkly between the base review and the ICP document were predominantly around discontinuing non-essential medication, 'prn' medication and antibiotic use in the last days of life (see Table 5.2).

Non-essential medication was discontinued in 46% of base review notes compared to two-thirds of situations during the study. PRN medication was only prescribed in 23% of case notes prior to the study contrasting with 93% when using the ICP documentation. Antibiotics were being continued in a third of residents compared to 5% during the study. The prescribing of antibiotics tends to give a pro-life message thus giving a mixed message regarding 'dying'.

Table 5.2 Differences to medication prescribing as a result of using ICP documentation

Non-essential medication discontinued		'PRN' medication prescribed		Antibiotic use in last days of life	
Prior to study n=30	Using ICP documentation n = 41	Prior to study n = 30	Using ICP documentation n = 41	Prior to study n = 30	Using ICP documentation n = 41
46	66%	23%	93%	33%	5%

The most common symptom recorded at variance to the stated goals on the 4 hourly on-going assessments of the ICP, was agitation. This confirms Hall et al.'s (2002) findings of a different symptom profile for older people dying at the end-of-life compared to people dying in mid-life from cancer. Agitation occurred in 24 out of 41 of the ICP documents and an anxiolytic was given to the resident in each situation. Because there is no 4 hourly assessment of symptoms made for residents dying in nursing homes where an ICP is not used, there is a danger that residents' agitation might not only not get recorded but more importantly not treated. In the base review, agitation was treated in 5 out of 13 residents (see Table 5.3).

Table 5.3 Change in recording/treating 'end-of-life' symptoms

	AGITATION		PAIN		RESP. SECRETIONS	
	Number of residents (%)	No. treated (%)	Number of residents (%)	No. treated (%)	Number of residents (%)	No. treated (%)
Using ICP	24/41 (58%)	24 (100%)	12/41 (29%)	12 (100%)	13/41 (32%)	13 (100%)
Prior to study	13/30 (43%)	5 (33%)	15/30 (50%)	10 (75%)	11/30 (36%)	2 (18%)

The other concerning feature is the use of an opiate for restlessness. At the commencement of the study, Fentanyl patches were used for five opiate naive residents. These residents were recorded as being 'agitated'. It was difficult to know whether the opiates had in some part caused the agitation. The apparent haphazard use of Fentanyl patches in opiate naïve residents in the last days of life needs addressing. In this study, the situations concerning the Fentanyl patches were addressed with the GPs concerned by the CNS/researcher. The practice of using an opiate at the end-of-life when pain is not an issue gradually decreased.

Pain is undoubtedly a problem for many older people in nursing home care where use of opiates may well be the analgesic of choice. However, dying in itself is not painful. Table 5.3 highlights that 12 residents (29%) were recorded on the ICP documentation as being in pain – far the greater symptom was agitation as previously stated. In the base review, a greater number of residents were thought to be in pain although this could now be debated as being agitation; but only three quarters of residents received treatment.

Hyoscine was used for a 'rattly chest' during the dying process in all thirteen cases (100%) it occurred when using the ICP documentation compared to two out of eleven (18%) of the reported situations in the base review.

Prescribing of anticipatory medication for end-of-life symptoms was in place for thirty two out of forty-one residents, with eight residents being prescribed all the different 'prn' medication to control pain, anxiety and respiratory secretions. In other situations it was generally an anxiolytic and medication for respiratory secretions.

"We get the pain regimes set up quicker, thinking ahead more, the doses and things, we've got everything set up ready..... But then it's not always just pain, it's agitation..."
[SN8/6, NH.F, final evaluation: para.119-121]

Of the nine residents who were not prescribed anticipatory medication when commencing the ICP documentation, GPs returned to the nursing home to prescribe medication for six of them. Three residents died without symptom problems and the need of any medication.

The overview analysis of the ICP documentation in the study highlights that palliative care knowledge around the control of symptoms for those dying in nursing homes continues to need updating. The Lothian Health Palliative Care Guidelines (2001) identify the differing symptom problems and the need of each symptom to be individually treated and so respect the differing dying trajectories (Hall et al. 2002). There is evidence that the nurses within the nursing homes are learning about and persuading their GPs to learn about the correct use of medication. However, greater collaboration on the part of GPs to be more involved in nursing homes remains an issue.

5.2.2 Changes made to the ICP documentation during the study

Changes made to the ICP documentation during the study were dynamic – 'tweaking' of the wording on the document occurred a considerable amount during the study until staff were satisfied (Appendix 15). The main changes made to the text concerned:

- The diagnosis of dying
- The prescribing of 'prn' medication
- Changes around the wording of the 'goals':
 - Changing 'double negatives' in the goal title
 - Giving more detail under some of the goals
 - Clarifying more appropriate wording

Ellershaw & Wilkinson (2003) rely on the input from the multidisciplinary team in their criteria for 'diagnosing dying' and commencing the ICP documentation within the hospital setting. Because of the lack of any regular multidisciplinary team being present in nursing homes, a further statement was added that *'those caring daily for this resident realise that the gradual deterioration and weakness of the resident despite all care is indicating that the resident will not get any better and that he/she is now dying'* thus encouraging nurses in their responsibility for end-of-life care.

As reported, the prescribing of 'prn' medication was a source of some difficulty - GPs were unused to anticipatory prescribing for symptoms at the end-of-life and sometimes did not know which particular drugs to prescribe. A change to the ICP documentation within the 'initial assessment' (Goal 2) now details the specific drug, dosage and route to control anxiety, moist respiratory secretions and pain.

Others felt that the original ICP documentation was still too 'cancer' orientated, despite changes from the earlier phase of the larger project (Hockley 2004b). They highlighted the difficulty of communicating with residents over their 'understanding what is wrong with them' because of cognitive impairment. The use of syringe drivers was also seen as equipment more likely to be used in a specialist palliative care setting rather than nursing homes. Many dying residents' symptoms were adequately controlled just by one or two doses of a certain medication. Out of the 41 ICP documents completed during the study, ten residents⁸ were prescribed drugs via a syringe driver. It could be argued that intensive courses on 'setting up syringe drivers' for nursing home staff especially in light of the high staff turnover and lack of regular use, might be better replaced by teaching on other aspects of end-of-life care.

Other changes around the headings given to some of the goals were re-worded. Some staff found the double negative in the heading difficult when charting a 'variance'. The goal 'the patient is not agitated' was changed to 'the resident is peaceful'. Also when it came to maintaining a 'moist and clean mouth' many carers were charting this as a variance. An older person who is dying rarely has a moist mouth during the last days of life. The goal therefore was changed to 'Mouth is clean'. Additional information was given to certain goals in order to enhance knowledge; in particular, the 12 hourly goals concerning religious/spiritual support and insight/psychological support for resident and family. Finally, a goal that 'any dressings have been attended to' was also added.

Being able to critique the documentation all together was really appreciated by staff, GPs and the study team alike, and allowed a more equal sharing of the power base.

*"And then through the sessions we actually got things changed in the sheets [ICP documentation], what we were talking about and that's, it all came about by discussion."
[CA. NH.A, final evaluation: para.266]*

5.3 STAFF PERCEPTIONS ON CHANGES IN end-of-life CARE

An 'audit' questionnaire containing 51 statements⁹ (Appendix 14) was devised from what staff had said was important to them about palliative care at the 'values clarification' exercise at the commencement of the study. This questionnaire was used to quantify staff's impressions on the effect of the study on their practice, and provide triangulation to the qualitative data. The questionnaire was slightly adapted for care assistants. Out of the 466 questionnaires sent out to nurses and care assistants in the eight homes, 139 were returned – a response rate of 30% (see Table 5.4).

⁸ Six residents had drugs via a syringe driver in the last days of life came from the same nursing home.

⁹ The statements were divided into 'before death' [11 statements], 'during death' [29 statements], and 'after death' [11 statements]

Table 5.4 Response by nursing home staff to audit questionnaire

Nursing Home	Number of audit questionnaires returned [n=466]	Nurse response	CA response
NH.A	15 (36%)	5/15	10/15
NH.B	2 (5%)	0/2	2/2
NH.C	26 (33%)	7/26	19/26
NH.D	17 (39%)	4/17	13/17
NH.E	33 (35%)	13/33	20/33
NH.F	9 (24%)	5/9	4/9
NH.G	10 (18%)	3/10	7/10
NH.H	27 (34%)	10/27	17/27
TOTAL	139 (30%)	47 (34%)	92 (66%)

A poor response rate is not uncommon in care homes. Redfern et al. (2002b) found that in order to get a good response rate to questionnaires it was necessary to get carers to complete them within the context of an interview. In this study key champions were encouraged to play their part in trying to achieve a reasonable response rate. As a team, there was probably only face to face contact with half the number of staff sent a questionnaire, so therefore the response rate was felt to be representative of those actively taking part in the study.

Data from the questionnaire were analysed using the Statistical Package for the Social Sciences computer software package (SPSS 2001) and descriptive statistics such as frequencies and percentages made for each statement (see Appendix 14). There were fifteen statements where over 70% of staff said that the study had specifically 'helped them to do the care better'. All of these statements were about the care 'during death' or care 'before death'. Staff appeared more comfortable with the statements 'after death' although this was the area also least covered by the study. In seven specific aspects of care, 80% or more of staff taking part stated that the study had either 'helped them to do it better' or that more importantly, they 'had only done it' as a result of the study (see Box 5.5).

Box 5.5 Aspects of end-of-life care most helped as a result of the ICP study

There is in-depth discussion and agreement about when a person is dying within the nursing home team; with GP colleagues; with the family and with the resident
The goals of care when a resident is dying are understood and we aim to achieve them
Staff keep their palliative care knowledge up to date
We have knowledge of different medication that can be used in the last days of life
We anticipate the symptoms residents have when they are dying
We have 'prn' medication available when someone is dying
We feel able to manage situations where there is some disagreement between key parties involved e.g. staff, GPs, families

These statements confirm much of the qualitative data around taking more proactive responsibility for end-of-life care and being more comfortable to discuss death/dying. The increased palliative care knowledge aided by the ICP document remaining in the nursing homes could continue to be a source of learning alongside practice.

There were fifteen statements where 50% or more staff felt the study had had no effect on care given (see Appendix 14). A majority of these statements regarded 'after death' statements where staff may well have felt more confident and, as already stated, where the study did not concentrate so much of the research. However, a few statements such as, 'we are able to put forward a case to management about the staffing levels to meet the changing needs when a resident is dying' and 'we ensure there is always somebody sitting with an imminently dying resident' clearly have an organisational element affecting the statement.

5.3.1 The ICP documentation as a tool

All the nursing home staff who came to the final evaluation were unanimous that the ICP documentation was an important checklist and guide to caring for a resident in the last days of life. In some nursing homes they felt that because there were not as many deaths as one might have in a hospice, the ICP documentation also helped as a reminder.

*"...when you've got a checklist it's all there to run through rather than just guessing...and running back and forward to the senior staff that are on...
[CA. NH.B, final evaluation: para.15]*

People felt there was something to reassure them that they were doing the right thing and it gave them increased confidence that what they were saying was correct. Where there were differing views about an aspect of care, the ICP documentation was consulted as it was seen as 'best practice' and evidence. The symptom control guidelines and other policy documents at the back of the ICP documentation aided this.

*"..Because we have recognised best practice, we don't have different views about what's best to do in certain circumstances and maybe someone has a different view because they have done it differently in the past. We have best practice and we follow it."
[SN. NH.C, final evaluation: para.47-51]*

*"I think people feel more competent and confident when they are in possession of the facts and they've got evidence to back up what they are saying."
[NHM. NH.F, final evaluation: para.155]*

Many talked about the documentation being an excellent teaching tool especially for carers. They felt it was well laid out and gave people a framework around end-of-life care from which to work and were pleased that death and dying was now being addressed in a structured way. It set out the goals that were to be achieved. Initially staff wanted to be able to see a column of 'A's indicating that the care goals were all achieved. The reluctance to acknowledge when a goal had not been achieved may have been a reflection of some staff's hesitation in criticising their own work. Without any critical learning culture there is a danger that the status quo never gets challenged. However, once grasped, the variance reporting was very much seen as a positive aspect of the documentation, and something that stimulated action in order to sort out the problem immediately.

*"...to have the variance sheet which actually commits you to responding to the variance and actually doing something about it within a given time frame was really, really helpful."
[KC1. NH.C, final evaluation: para.238]*

"So the fact that you have to put the variance on there all the time makes you act on that instead of saying OK I'm finishing my shift in 15 minutes...I'll pass it on to the next person, the whole idea that things get done there and then, you can't keep on postponing it, which was I think one issue that happened most of the time, not just with the last days of life...urine specimen needs to be sent, I'll pass it on to the next person but in the last days of life the ICP makes you deal with the incidents as they happen so you can't postpone it."

[KC1. NH.A, final interview: para.87]

One key champion had felt at the beginning of the study that the ICP documentation would merely be confirming the care that they were already giving. However, six months later the same key champion was not only admitting that the culture towards death and dying was more open in their home, but that the ICP documentation helped them to control symptoms at the end-of-life.

Carers in three different nursing homes spontaneously reported that before the implementation of the ICP documentation they just relied on 'commonsense'.

"It covers more things than we covered before. Before we've just been using common sense and TLC."

[CA. NH.A, final evaluation: para.19]

However, for some it was strange to be making a decision that someone was dying. Initially it was thought by one carer to be 'euthanasia' until things were discussed in more depth.

Prior to the study talking to families was often seen as work done behind the scenes. The ICP documentation encouraged the work with families to be seen as important as the physical care for the resident.

" I think it ties it more neatly together if you like than what our old record system did. The documentation that the ICP is...I like the way it is laid out, and talk about all the things that you do behind the scenes, so to speak, you know like talking to families, contacting families that kind of thing and I think it's more easily viewed." [

KC. NH.B, final interview: para.29]

" Yes it's a really, really good tool because it makes us as nurses have to think about the whole process and what happens within it."

[SN3. NH.H, final evaluation: para.13]

Getting GPs to prescribe in anticipation of symptoms in the last days of life was not helped by the fact that prescribing drugs for a resident that were then not used was seen as a waste. A couple of nursing homes were in favour of a special box of terminal care drugs to be kept in the nursing home as stock. Unfortunately, nursing home policy around drug administration has not been reviewed since nursing homes were first regulated. The changing nursing home context with an increasing number of deaths may mean this needs re-examining.

5.4 SUSTAINING CHANGE IN END-OF-LIFE CARE

The study was designed in such a way that any developments in end-of-life care in the nursing homes would hopefully be sustained. One of the main components was the appointment of key champions as 'insiders' in each nursing home. They were supported through the change initiative in such a way as to promote empowerment and greater ownership of the developments being undertaken (Balfour & Clarke 2001).

As the research team withdrew from the nursing homes, evidence from all data collected was examined to see what might support/hinder sustainability of the changes that staff in nursing homes had undergone through the life of the study. There were four areas:

- Empowerment of key champions and organisational change
- Knowledge into practice
- The important role of the care assistant role
- External support

5.4.1 Empowerment of key champions

Developments within the key champions themselves were an important sign of their feeling empowered. One of the main roles of the facilitators in the study focused on 'enabling others', with particular encouragement for 'critical' reflection. By specifically appointing key champions as 'internal' agents, they were now a potential resource within the nursing homes that would hopefully help to sustain the changes made as a result of the study. One key champion saw herself as having 'crossed a hurdle' and was very ready to take on further challenges.

"...and aiming higher than this because I think, I know that I am capable of it, you know because sometimes at the beginning you don't know how it is going to go, so I feel I am capable of doing it and I could do even better than this so, it's a beginning for me."
[KC. NH.A, final evaluation: para.131].

This key champion had taken the initiative to start to put together an information booklet for bereaved relatives. She and a colleague had also distributed a questionnaire asking staff which areas of palliative care they needed most help with.

Another key champion felt she had gained knowledge in how to effect change.

"And there's been a lot of knowledge I've picked up through the process about how to effect change so I think the process is as important as the outcome...."
[KC1. NH, C final interview: para.70].

Despite trying to develop specific facilitation skills with the key champions during the process of action learning, none of the key champions felt able to carry on such a process in their own settings. They stressed that the main reason for this was their recognition of the skill required by a lead facilitator to manage such an approach to learning. Some key champions, however, did realise that with determination they were more able to challenge the management, and change things in their nursing home for the better.

"I think there's been a few things change because one of the things that I didn't really like in the nursing home was the business about a resident dying and it was sort of, they went out the back door kind of thing...I always had a thing about that. I think when we started with the ICP it gave me that bit more determination that this was going to be different and I think they are taking that on board now."
[KC1. NH.E, KC's interview: para.125]

The key champions were certainly instrumental of some organisational change that they felt they themselves could influence. However, many key champions were not in a position of formal leadership in the organisation and found it difficult to influence change such as 'time constraints' and 'staff shortage'.

One of the questions which all nursing home managers were asked in their final questionnaire was how easy they thought it would be to sustain the focus on end-of-life care in their nursing home. Those managers of nursing homes where only one or two ICP documents had been completed thought it would be quite difficult. Two in particular identified time constraints, the day to day running of the nursing home, and difficulties of getting staff, particularly new staff, trained in using the ICP documentation, as being the main barriers to sustaining the change to the way end-of-life care was now being managed. Inadequate staffing and time constraints will remain difficulties preventing innovation within the nursing home context unless different leadership styles and effective teamwork are considered (McCormack & Garbett 2001).

Even though all of the nursing homes in the study were planning to continue using the ICP documentation at the end of the study, realistically it is most likely that this will only occur in nursing homes where the ICP documentation actually became embedded in the organisational culture.

*"I think if it just becomes an integral part of how you work...it's not a case of will we or won't we but just, as of now this is part of our nursing process and this is just what's done."
[KC2. NH.D, final evaluation: para.306].*

In one nursing home not only did the nurse manager feel that other staff might be inspired to champion other developments within the home because of the success of the study, but also as a company, they themselves plan to roll out the ICP for the last days of life document throughout all nursing homes in the group. They plan to replicate the model of change management used in this study and the nurse manager is planning to use staff involved with the ICP study to be part of this challenge.

The importance of recognising the role of a nurse with palliative care expertise who is able to act as a resource within the nursing home setting itself was acknowledged by still a further nursing home. This nursing home has already sent a number of their staff on validated palliative care courses. Now that they have the resource of a specific nurse ready to 'take on' promoting palliative care within the home, their vision that palliative care will become a major focus of the care of their residents is more likely to be achieved.

A further nursing home had integrated 'end-of-life care' and the ICP documentation into its orientation program. They also changed their day-to-day documentation of care to reflect the achieving of goals/variance akin to the ICP documentation.

5.4.2 Knowledge into practice

Gaining new knowledge in isolation of practice-based intervention is known to have little impact on both medical and nursing care (Boakes et al. 2000; Froggatt 2000). The emphasis in the study to share palliative care knowledge within each nursing home, alongside the implementation of the ICP documentation and facilitation of key champions, was a deliberate attempt to acknowledge this. One key champion who had previously completed a palliative care course at the hospice talked about how being part of the study had helped her to 'make more of the course'. She found that it had provided a way for her to put her knowledge into practice [KC.NH.F final interview: para.9] and emphasises the importance of synchronising education and practice development initiatives.

In the majority of the nursing homes, death and dying had become less peripheral and the staff had gained knowledge in end-of-life care through being involved in this multi-faceted way.

"The support that we have had from the hospice has been great because it has helped us to gain confidence and knowledge especially about things like drugs and doses and just when we should be starting, because every individual is different so how the last one went, this one isn't the same, so being able to phone and say look can you give us a bit of guidance here, I found that a great help."

[SN. NH.C, final evaluation: para.196].

Once knowledge and interest in quality end-of-life care had been stimulated, the ICP documentation became a tangible structure that was left in each nursing home at the end of the study. Staff felt that such a document with the variance reporting encouraged critical thinking around end-of-life care issues and allowed them to put new knowledge into practice more easily.

"We've got more control, more empowered if you like, all of us because, you know we are taking control of the situation and saying, this is a variance... if it's not quite right then you do something about it...knowledge, you've got some knowledge...and you deal with things better...it's the knowledge."

[SN. NH.A, final evaluation: para.170]

In this study the ICP documentation provided staff with a structure within the organisation upon which their new knowledge could be supported. As long as the ICP for the last days of life document continues, it could be a resource not only to encourage critical thinking but to serve as an evidence-base for best practice in quality end-of-life care.

5.4.3 The important role of the care assistant

The study highlighted that care assistants are a rich resource – a fact which may have been overlooked in some nursing homes. Care assistants in particular have a very close relationship with their residents, which is a unique aspect of nursing/care home work (Irvine 2000). Not only were care assistants involved in the group work, but were given responsibility for the ICP documentation itself. Many carers 'blossomed' by being involved in the study and this change was recognised by managers.

"I think I have realised that some of my carers are much more able than I thought. I plan to extend their responsibilities in the future."

[NHM. NH D, final questionnaire].

"I think that the work that has been done since the ICP...has created yet another change. The carers in particular feel they are much more consulted. I think that they feel that there is a way of justifying that what they have been doing is worthwhile, it is very necessary and that their role is very, very essential. I think because they feel like that they feel much more comfortable and less frustrated."

[NHM. NH.E, interview: para.79]

The study had satisfied a desire within many of the carers to attain more knowledge, feel more valued and even fulfil their potential. These are components that Senge (1990) refers to as necessary for a learning organisation. Redfern et al. (2002b) highlight the importance of addressing 'burnout' and 'rust out' in care homes, not only because of high turnover of staff, but also because of quality of care impacting on residents. The eagerness with which care assistants responded to the study illustrates an important role that practice development may have in preventing 'rust out' in nursing homes.

"We are going forwards, we are not going backwards, the more knowledge you get and the more experience, the better...we are not taking a step backwards, we are taking a big step forwards."

[CA2. NH.A, final evaluation: para.257]

Other carers were beginning to recognise the importance of supporting one another formally if they are to stop good carers from leaving.

*"I can think of one girl... she's a good carer but she is so scared of someone dying. And I think you have to start her right at the beginning."
[CA. NH.G, Final evaluation para.155].*

The process of the study in itself made the key champions in one nursing home realise the importance of nurturing the carers, and even to think about how else they might apply what they had learnt through the study to other areas in the nursing home.

*"But it has made me wonder, you know, because it has formed part of a structured learning process, what we could get out of the carers if we carried that sort of practice into other parts of the work we do, and it does make me question how good we are at doing all the education stuff and staff support stuff, I think it's opened my eyes to some of the weaknesses in the organisation and the weaknesses in the service we provide. [The ICP] stands out as something we do really well and everybody gets so enthused about it. But they could equally get enthused about the other things that we do as well."
[KC1. NH.C, final interview: para.68]*

Harnessing this enthusiasm of the core group of carers in each nursing home was a building block for sustainability.

5.4.4 External support required to sustain change.

Aspects of the study that contributed to its success were the clinical support, the collaborative learning groups and the action learning. If the changes made are to be sustained in light of the 'weak' context, then it is likely that some initial external support needs to be continued. The team felt that since in-depth work with the eight nursing homes only continued for nine months, and in some less than this, many of the study nursing homes were still quite vulnerable in their new knowledge and attitudes to end-of-life care.

The ongoing training of staff because of the high turnover was an issue that the homes identified as being necessary for them to address, in order to maintain the changes. This issue is perhaps too big for the nursing homes staff on their own to cope with. They all said that continued support from the CNS/researcher would help them sustain the changes. Unfortunately, local specialist palliative care input is only on an 'as requested' basis without any formal, regular input for practice development. end-of-life care in nursing homes is in the very early stages of development, and there is much still to be achieved which cannot necessarily be 'taken up' by existing specialist palliative care services. The ongoing clinical support and continuing education and training in this area of palliative care are essential if older people are to receive the quality end-of-life care.

One of the main hindrances to sustaining change in this study has been the lack of GP time and therefore perceived lack of co-operation. Even though key champions had encouraged their GP colleagues to come to the introductory talk about the study, this only happened in two nursing homes. By the end of the year, some nursing homes still did not have all their GPs entirely on board. The nursing homes identified this as a barrier to them sustaining the changes they had started to make. They want greater collaboration with medical colleagues in order to provide quality end-of-life care for their residents rather than just remain with the status quo. However, many GPs feel that their service is already overstretched by the increasing burden of frail and dying residents in care homes. Greater attention to the arrangements for GP support in care homes are needed (Sidell et al. 1997; Groom et al. 2000).

5.5 SUMMARY

This chapter has looked at how through the whole study of the implementation of the ICP, caring for dying residents became less peripheral to nursing home care. The naturalness of dying at the end-of-life was better understood. Staff within the nursing homes, including nursing home managers, were taking more responsibility for the important care necessary in the last days of life. By creating an open culture around death and dying, the dying process was more easily recognised such that more proactive care was given. The increased knowledge gained by staff around palliative care nursing and the drugs to control distressing symptoms at the end-of-life, gave them greater confidence to speak about dying – not only amongst themselves but as appropriate with residents, and in particular with relatives. Above all, the evidence suggests that using the ICP documentation to guide end-of-life care can aid better control of symptoms and improve teamwork.

The multiple medical pathologies exacerbating the palliative care needs of older people in nursing homes require a multidisciplinary approach. As a result of the study, the key champions and many of the staff in the nursing homes were motivated to take more responsibility, but GPs are a vital component of the team to ensure that appropriate medication is prescribed for end-of-life care.

At the closure of this study, there is evidence that the model of facilitation used has achieved a more than satisfactory outcome. All nursing homes plan to continue using the ICP documentation. Key champions will remain a key part of the documents' sustained use, alongside the important role of the care assistant already highlighted. A 'weak' context in some of the nursing homes may mean that there is more risk than others for its continued use. However, the core staff in each of the nursing homes who came together for the study remain individuals who have the potential to continue to change the end-of-life care in nursing homes. Considering the limited time-scale of the study, the staff achieved a real shift in both their attitudes and practice towards quality end-of-life care which, given the support of local GPs, has the potential of embedding the ICP and its use in routine practice.

Chapter 6

Conclusions and Recommendations

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 participating nursing homes, dying became less peripheral to the care culture. Facilitating the ICP documentation as a way of developing end-of-life care encouraged a greater openness around death and dying, with the direct result that nurses and carers were prepared to take greater responsibility for recognising dying and marking the dying process. The process encouraged a greater sense of teamwork, valuing the care assistants' role, and challenged 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 (see Diagram 6.1).

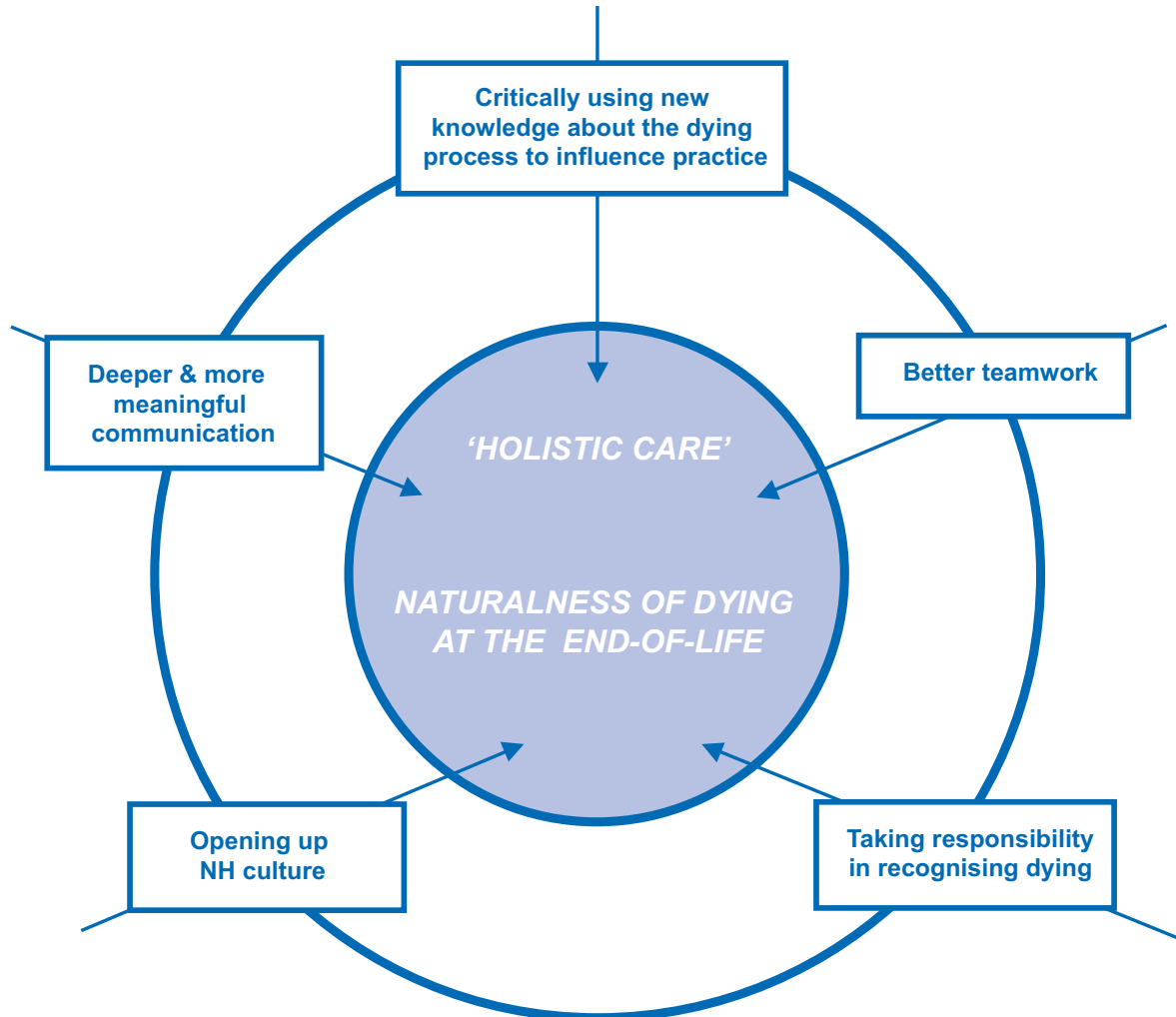
The enthusiasm encountered during the study was very real and highlights how important the subject of 'death and dying' is to staff working in nursing homes. For some of the staff the study even appeared to rejuvenate them in their caring. However, it must be stressed that the nursing homes in this study were likely to be more 'open' to change since they had volunteered to take part. There is concern that other nursing home, because of their isolation from clinical expertise, practice development and education in palliative care, may unintentionally and unconsciously be harbouring considerable suffering at the end-of-life.

As a result of the study, we would suggest that the ICP documentation does make a number of assumptions which are important when using the documentation to develop quality end-of-life care in nursing homes, namely: that nursing home staff know when someone is dying and understand the dying process; that nursing home staff are familiar with palliative care drugs; that nursing home staff are confident in communicating about dying; and, that there is good multidisciplinary team working in nursing homes. Froggatt (2001b) highlights the danger in assuming that the hospice model of palliative care can be transferred directly into the nursing home context. In the same way, there is a danger that implementing the ICP without acknowledging the differing context risks losing the uniqueness of a particular setting, in this case nursing homes. The emphasis given at the beginning of this study to understand the context enabled these assumptions to be addressed, and brought about a change to the day to day practice of end-of-life care. It also provided an opportunity to add to the theory around dying. However, changes within the nursing homes as an organisation were limited, and difficult to influence.

The overall context of nursing homes is complex. Not only are staff shortages, time constraints and low morale endemic in nursing homes (Redfern et al. 2002b; Teno 2003), all of which were issues in the study homes, but the workload of GPs in the community impacts on how much time they can give to staff and their residents (Groom et al. 2000). The 'context' issues experienced in the study will, to a greater or lesser extent, influence sustainability but problems of context must not diminish the importance of practice development initiatives, particularly in independent nursing homes. Some of the discontent in nursing homes is as much about 'rust out' as it is about 'burn out' (Nolan & Grant 1993). It may just be that such practice development initiatives can challenge the lack of a learning culture and so help, in the long term, to counter 'context' issues.

Developing quality end-of-life care in 8 nursing homes through the implementation of the 'ICP for the Last Days of Life' created a more central and a less peripheral focus to end of life care in nursing homes.

[Diagram: 6.1]



"...it's a lot more relaxed and people aren't so frightened...it's been a really successful thing in bringing death and dying to the fore and not to be so frightened of it"

[SN3. NH.H, final evaluation: para.63]

Greater valuing and support of staff already working in a nursing home especially in light of the greater number of deaths now occurring in nursing homes is fundamental. The denial of dying evident at the beginning of the study may have been a way of coping with the increase in deaths, but without the necessary support and the knowledge to address fears.

Staff stress is heightened when common symptoms such as agitation at the end-of-life are not controlled. There is concern over the amount of opioid medication, especially Fentanyl, being used to control agitation in the last days of life on opiate naive residents. The study strongly indicates a need for more in-depth palliative care training, especially around dementia and palliative care for some GPs. This study confirms Hall et al.'s (2002) theory that older people have a different dying trajectory compared to those people dying in a less timely way from a disease such as cancer. The ICP documentation is possibly a tool that, because of its 'critical' use of variances, may be used to research this difference.

Greater collaboration and organisational efficiency needs to be addressed between nursing homes and their GP practices in light of the increasing burden of palliative and end-of-life care. The lack of a working 'relationship' with GPs in some nursing homes compounded the 'integrated' issue of the ICP around end-of-life care. Where possible, a single GP practice visiting one nursing home would help continuity of care and the building of a relationship with staff and residents. However, such a structure must be well coordinated with nurses being prepared to take greater responsibility for the palliative care needs of their residents. Equity in good medical care is as much an ethical argument as is the choice of GP. A minority of residents may specifically want their own doctor because of a particular 'relationship'. This argument becomes more redundant given the fact that GPs 'out of hours' service is now managed by call centres and covers 75% of the week.

Providing appropriate facilitation in a study that involves change is crucial to its success (Dewar et al 2003; Kitson et al 1998). This facilitation can, of course, take many forms, and in this study it included action learning sets, collaborative learning groups following a death in the nursing home, and regular support from the CNS (palliative care) and the 'core' research team. The action learning was effective in the main in achieving its objectives. These were to: not only provide support, but to get at the heart of issues that were having an impact on practice; challenge beliefs, values and assumptions; and help the individual to be empowered to make changes in their practice. There were organisational and cultural barriers which did not make change easy but which needed to be addressed. Action learning helped some key champions to start to address this.

For further development to occur, the nursing homes using the ICP documentation need continued support, both clinically and educationally, within and outwith the nursing home. Nine months was not long enough to fully embed the ICP documentation, despite the use of key champions in all the eight nursing homes, in a complex context where the majority of staff are untrained. With the nursing home becoming the place where older people die (Teno 2003), managers need to be prepared to give 'official' support in the form of appropriate palliative care education and clinical expertise, in order to provide quality end-of-life care. Adopting a style of management such as that of a 'learning organisation' (Senge 1990), where the emphasis is on a flatter management structure, could be appropriate. Nursing homes have the opportunity to become places where 'nursing' can come into its own, as long as staff are motivated and supported.

Finally, we are aware that this study was very much an integral part of the previous phases of the project, and the marketing of a new education programme for palliative care/older people. The importance of education for individual learning is vital but practice development initiatives need to work with this learning to bring about change in practice. Nursing home work carries a lot of responsibility for the care of older people at the end-of-life. Staff who work in nursing homes work there because of

a real desire to help with the daily needs of those too frail to be able to do things for themselves. We need to strive to make sure that care in the last days of life is more equitable for all.

6.1 RECOMMENDATIONS

The implementation of the ICP for the last days of life document, with the wider project of developing end-of-life care in nursing homes, showed that nursing homes have the potential to provide quality end-of-life care for older people. However, certain recommendations are highlighted below.

6.1.1 Recommendations for end-of-life care in nursing homes

Palliative care as part of induction/mentoring for nursing home staff.

Systems need to be in place to ensure that palliative and end-of-life care play a greater role in the induction/mentoring of nursing home staff. Most residents now being admitted to nursing homes require 24-hour nursing care, and are suffering from advanced progressive disease/s requiring palliative care.

A strategic approach to encourage nursing homes to form 'working relationships' with one local GP practice.

The study showed evidence that where a working relationship had developed with one GP practice, there was greater use of the ICP and better prescribing for end-of-life care. A 'relationship' with work colleagues helps to provide a better service (Davies 2000). Greater attention to regular arrangements for medical cover, with one GP practice per nursing homes is recommended.

An emphasis on greater patient-focused/person-centred approach to care in nursing homes

Palliative care is founded on a holistic approach to care that considers the physical, the psycho-social and the spiritual needs of patients and their families (Saunders 1984). An emphasis on the needs of individual residents should be given over and above 'getting the work done'.

A process is undertaken to encourage a greater learning culture in nursing homes.

This study has shown that staff in nursing homes were eager to learn about quality end-of-life care through the implementation of the ICP, and that this appeared to re-energise staff. Much of the discontent in nursing homes is as much about 'rust out' as it is about 'burn out' (Nolan & Grant 1993). Encouraging a learning culture is one way of supporting staff; for example, the collaborative learning groups in this study helped to fulfil not only a point of reflective learning about the care given to dying residents, but provided an opportunity for greater support and communication across the team. Macmillan Cancer Relief (2004) have produced a 'step by step' foundation course in palliative care, which is a programme of facilitated learning, and is available 'free' to all care homes in the UK. Such a programme supports learning within the care home whereby staff can learn together as a team. There are other palliative care courses – some specific to the palliative care needs of older people, for example St Columba's Hospice, Edinburgh [<http://www.stcolumbashospice.org.uk>] and Queen Margaret University College, Edinburgh [<http://www.qmuc.ac.uk>]. However, it would seem that where an education initiative is synchronised with a practice development strategy there is increasing likelihood to bring about change in practice.

A greater awareness of the knowledge of drugs available to control symptoms at the end-of-life

Knowledge about available palliative care drugs and their appropriate use/dosage to control agitation, respiratory secretions and chronic pain when a resident is dying needs to be improved. Local palliative care guidelines already exist in Lothian (Lothian Health 2002) and all nursing homes have a copy, but

unfortunately the folder more often than not remains unused on a shelf. Printing the guidelines printed out in the back of the ICP document meant that they were more accessible. A simple education initiative such as a 'road show' or a local hospice initiative for GPs/nursing home staff could illuminate greatly the control of symptoms in end-of-life care.

A re-examination of the legislation around drugs for end-of-life care in nursing homes.

At present it is not legal to keep as 'stock' terminal care drugs in nursing home, despite the increasing number of older people who now die there. Guidelines such as the ICP suggest the anticipatory prescribing of medication so that symptoms of distress are controlled without delay, and the call out of doctors who do not know the resident especially at week-end and overnight is prevented. For example, as suggested by a couple of GP practices, a box of 'terminal care drugs' could be supplied by the local pharmacy when a resident is to be commenced on an ICP. When the resident dies, the box would be returned to pharmacy for storage and replenishment. This would prevent wastage of anticipatory medication being prescribed and then, as is sometimes the case, not used.

A strategic approach to connect independent nursing homes to innovative palliative care practice

Nursing homes within the independent sector are isolated from innovative palliative care practice (Gibbs 1995; Sidell et al. 1997). A concerted effort needs to be made to prevent isolation and to build bridges between the independent sector and the NHS. An example of this would be to make formal links, with the establishment of a multi-disciplinary team to help support the clinical, research and practice development needs around palliative care in nursing homes. Such a team would comprise nurse specialists (palliative care/gerontology), pharmacist, rotating SPRs (specialist practice registrars) in palliative care/mental health/older people medicine, and others.

Re-evaluate the 'for profit' status of nursing homes

Nursing homes carry out very important work providing the major care for frail older people in the UK – 55% of whom die within two years of admission to a nursing home (Sidell et al. 1997; Hockley 2004a). However, their 'for profit' image of making money out of vulnerable older people can be perceived as inappropriate. Over the last ten years, with increased legislation regarding fire regulations, category status etc., many independent nursing home owners, especially the non-corporate types, struggle to make ends meet (personal communication). Money cutbacks affect patient care. It is suggested that 'not for profit' businesses might be more appropriate in order to attract greater local community support for the work they do.

6.1.2 Recommendations for those interested in implementing 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 nursing home is recommended.

We would draw attention to the evidence, facilitation, context framework (Kitson et al. 1998; McCormack et al 2002) specifically used in this study. It is recommended that this framework is used prior to implementing evidence-based guidelines, in order to understand barriers which can then be highlighted and steps taken to overcome them.

The facilitation process used to support staff in the implementation of the ICP must challenge staffs' assumptions and beliefs.

Nursing home managers wanting to implement an 'ICP for the last days of life' should consider the importance of the following:

- Encouraging a dialogue about the ICP documentation with the GP practice/s prior to commencing its implementation.
- Appointing suitable 'key champions' to guide the implementation within the nursing home
- Supporting the 'key champions' during the change process in an environment that challenges assumptions and beliefs about end-of-life care and bringing about change
- Providing initial in-depth training from a specialist in aspects of end-of-life care such as 'diagnosing dying', control of distressing symptoms and the reporting of 'variance' from the pathway is paramount.
- Undertaking appropriate reflection on each ICP documentation alongside specialist palliative care support following the death of a resident in order for people to learn from completing the documentation

The ICP document is a useful tool for auditing quality end-of-life care in nursing homes as a basis for practice development.

Having a tool such as the ICP as a guide/checklist can help to provide nurses/carers with a model for 'best practice'. Such a tool can also be used as an audit tool around the differing aspects of end-of-life care i.e. communication and involvement with relatives, spirituality, control of distressing symptoms, involvement of GP practice in prescribing for end-of-life care. Any re-occurring difficulties can be seen as important educational needs.

6.1.3 Recommendations for further research in end-of-life care in nursing homes

Further projects as a result of the study

In order to capitalise on this study, further projects could be undertaken whereby nursing homes that have embedded the ICP in their practice could develop smaller projects around end-of-life care which would be formally evaluated.

Research on the holistic care and in particular the spiritual/pastoral needs of residents at the end-of-life is indicated

In this study the importance of religious ritual and spirituality at the end-of-life has been highlighted by staff, residents and families. Care homes are often referred to as 'Heaven's waiting room' (Forbes 2001). The pastoral work for residents in nursing homes is relatively unresearched.

Further research looking at 'after death'

This study focused attention on 'before death' and 'during death', but had limited scope to examine the effect of a resident's death on other residents in the nursing home. Grief work plays an important part in the recovery of family and friends of people who die from cancer in mid-life. However, it is relatively unknown what impact the death of another resident has on a close resident in a care home, and the impact a death has on family members.

More in-depth research is suggested to address the differences in the dying trajectory of older people.

More in-depth research is required to address the differences in the dying trajectory of the very old compared with the pattern of death observed for example from cancer in mid/late life. Assessments of such differences are at present very subjective.

The role of a nurse practitioner in gerontological palliative care within the nursing home structure as a means of enhancing the clinical role of nursing in this setting requires investigation.

Initiating and evaluating the role of a nurse practitioner in palliative care, through a practice development initiative in a nursing home, could have important implications for raising the profile of clinical positions rather than always those of managerial positions in nursing homes.

Research into the role of leadership in nursing homes

Researchers in this study were aware of the stress of working in nursing homes 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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