Developing high quality end-of-life care in nursing homes: an action research study

Jo Hockley

Thesis presented in fulfilment of the requirement of the
degree of Doctor of Philosophy

THE UNIVERSITY OF EDINBURGH
2006

ABSTRACT

This thesis provides an account of an action research study undertaken to develop staff knowledge concerning high quality end-of-life care for older people resident in nursing homes. Two independent nursing homes (NH1, NH2a & NH2b) volunteered to take part. In each nursing home, an exploratory phase was undertaken using focus groups, interviews, participant observation, and documentary analysis. This exploratory work confirmed specific contextual and clinical issues related to end-of-life care and highlighted that dying was peripheral to the nursing home culture where the emphasis was on functional rehabilitation. In each home, an initiative, inductively derived from discussion with staff and based on the exploratory phase, was devised and implemented. In the first nursing home, the initiative entailed development of 'collaborative learning groups' (CLGs) which took place following the death of a resident; in the second home, the adaptation and introduction of an 'integrated care pathway (ICP) for the last days of life' to be used *prior* to the death of a resident, provided a system around which high quality end-of-life care could be promoted. Both actions were evaluated. These initiatives enabled a greater openness towards death and dying in both nursing homes.

A model for developing practice is presented combining these two inductively derived initiatives that acknowledge the importance of both the lifeworld of staff in their care of dying residents and their families and the nursing home system. This model, and the process of undertaking the action research, is discussed in relation to Habermas's Theory of Communicative Action – a substantive theory of 'system' and 'lifeworld'. Implementing the ICP as an integral part of a system for end-of-life care within the rehabilitative culture of nursing homes, and facilitating learning through a CLG after a resident dies, *both* (and importantly, together) encourage the development of staff knowledge and their support of each other in their care of dying residents. Previous research studies in this area of care have, in the main, only described the quality of end-of-life care in nursing homes; a few studies have tried to influence such care through education and clinical involvement. This study makes a contribution to knowledge on the basis of it being an action research study in two nursing homes focused on the process of trying to change a functionally orientated rehabilitative culture to one that is more open to staff needs in the delivery of high quality end-of-life care. Findings of the study are discussed in relation to wider political and development issues; namely, the responsibility that nursing homes now have in the end-of-life care of older people; the importance of greater openness by management of nursing homes in their recognition of death and dying as an integral part of the culture and their subsequent support of staff; the unique role that nurses in nursing homes have to promote quality end-of-life care; and the need for targeted practice development initiatives within nursing homes to encourage better knowledge of symptom control and end-of-life issues that are specific to the care of older people dying in nursing homes.

DECLARATION

I hereby declare that this thesis has been composed by me and is entirely my own work.

Jo Hockley
January 2006

This thesis is dedicated to Dame Cicely Saunders, whose work inspired me to pursue a nursing career in palliative care.

ACKNOWLEDGEMENTS

I am deeply grateful to a number of different people for their support throughout the work involved in undertaking this thesis.

I am particularly indebted to the staff, nurse managers and owners/management of the two independent nursing homes involved in this study who so willingly gave up time, often outside working hours, to collaborate; to the residents who allowed me to work alongside staff in their care and the relatives of those residents who were dying who willingly shared and talked to me about what was important about end-of-life care.

I would like to thank my supervisors, Professor Alison Tierney and Dr Steve Tilley, who helped to get the study started and Dr Alex Robertson who 'stepped in' when Alison left to take up another position; for all their invaluable advice, encouragement and the correction of my English grammar! I thank also Dr Desmond Ryan, whose wider experience of action research, and whose wisdom and insistence on the value of postgraduate writing groups was a very real support; and, of course, my PhD buddy Erna H.

I am also very grateful to the Board of Governors at the Hospice for funding me during the undertaking of the Bridges Initiative project and the subsequent PhD thesis; to members of the steering group who met regularly throughout the duration of the project and for their support and interest in the thesis; to Helen D, Margaret C and Ish W for their constant encouragement and wisdom; to Belinda D who was instrumental in early discussions of the project with Margaret C around its action research focus, and Belinda's subsequent support in helping me to 'get to grips' with action research as a methodology. I would also like to acknowledge the opportunity provided by the action research group at The City University, London who were a source of much encouragement and information about action research.

I would like to mention particularly the support from a whole host of friends and family both here in Scotland and 'down south' for their support. I would especially like to thank Keith F and Hans C who suggested I apply for the project in the first place; Katherine F for her constant encouragement, and the opportunity we have had to promote the palliative care needs of older people in care homes together and for the growth we have made in understanding the importance of action research in nursing. Finally, I am grateful for the distraction of another project throughout the duration of this study; for the help and support given by my twin sister, Sally H and a friend Eleanor C; and for the love and financial support from my brothers and mother especially during the final phase of writing this thesis.

CONTENTS

CHAPTER 6: FACILITATING CHANGE THROUGH 'COLLABORATIVE LEARNING GROUPS' 144

CHAPTER 7: FACILITATING CHANGE THROUGH THE INTRODUCTION OF AN 'INTEGRATED CARE PATHWAY' 185

GLOSSARY:

AR	Action research
BGS	British Geriatric Society
CA	Care assistant
CLG	Collaborative learning group
CNS	Clinical nurse specialist
CXR	Chest x-ray
D	Domestic

Dual registered care homes – a care home registered to admit residents who need either nursing care or just personal care

DoH	Department of Health
ECG	Electrocardiograph
EofL	End-of-life
FG	Focus group
GP	General medical practitioner
ICP	Integrated care pathway
JH	Jo Hockley
LCP	Liverpool Care Pathway
N	Nurse
NH	Nursing home
NHs	Nursing homes
NHS	National Health Service
NM	Nurse Manager
NN	Night nurse
PAMs	Professionals allied to medicine
'prn'	given if required

RCN	The Royal College of Nursing
RCP	The Royal College of Physicians
RMN	Registered mental nurse
RN	Registered nurse
RNHA	Registered Nursing Home Association

CHAPTER 1

INTRODUCTION

'All the world's a stage,
and all the men and women merely players:
they have their exits and their entrances;
and one man in his time plays many parts,
his acts being seven ages.....
Last scene of all, that ends this strange eventful history,
is second childishness and mere oblivion,
sans teeth, sans eyes, sans taste, sans everything.
Shakespeare: 'As You Like It', II.vii.p139

This thesis details a 3-year 'journey' taken by myself along with staff working in two independent nursing homes[1] (NH1, NH2a and NH2b) to develop and improve the quality of end-of-life care being given to residents who were dying. I call it a journey because of the changes that occurred in me and those who took part: we learnt more about ourselves, more about the knowledge and practice of end-of-life care for older people in nursing homes, and more about the whole process of bringing about change.

The opportunity to undertake this study came about as a result of an announcement from the Scottish Executive in 1998 that they were to fund a limited number of two-year projects to disseminate specialist palliative care knowledge into the generalist setting.

---

[1] Currently it is not particularly 'fashionable' to use the expression 'nursing homes'. Following the publication of 'National Care Standards for Care Homes for Older People' (Scottish Executive 2001), nursing homes and residential homes became renamed as 'care homes'; a significant difference, however, remains between residential care homes and those that provide 'nursing'. For the purpose of this thesis, the flow of the text, and because 'nursing' most aptly describes the care being given by staff in the nursing homes in this study, the phrase 'nursing homes' is used. However, where residential and nursing homes are referred to together, I use the expression 'care homes' to cover both.

Many hospices in Scotland put in proposals – including the Hospice[2] which funded this study. The proposal from the Hospice related to an initiative to develop palliative care in local nursing homes using action research. The Scottish Executive did not fund the Hospice's proposal. However, because of an increasing pressure on the Hospice to admit older people, whose cancer then did not progress quickly, the Executive Board decided to fund a nurse specialist to lead a 5-year project in order to develop palliative care[3] within the local nursing home setting. The Hospice management's rationale behind the project was to explore nursing homes as an alternative place of care in order that older people not imminently dying could be transferred to a nursing home interested in providing palliative care; thus reducing pressure on their own beds. When appointed to the project, I was given the opportunity to use the project as an opportunity to study for a PhD. This thesis is the product of the research carried out.

Local health board statistics for period 1989-1998 (LHB, 1999) revealed that the number of people dying in independent nursing homes had increased nearly fourfold, whereas the number of people dying at home or in hospital had decreased over the same period. [see Table 1.1].

The passing of the NHS Community Care Act (1990) has resulted in an increasing number of older people being cared for in an increasing number of care homes. Although older people are being cared for for longer in their own homes, those requiring 24-hour nursing care are now frailer when admitted to nursing homes. This development and the increased number of nursing homes becoming available during the 1990s are probably the reasons for the increased number of deaths in nursing homes.

---

[2] The name of the hospice which funded this study is known as 'the Hospice'. Where the generic name for hospice is used the word is spelt with no capital letter.

[3] 'Palliative care', explored further in Chapter 2, is a term that can mean different things to different people. Prail (2000) highlights the growing change in terminology that has occurred over the years since the beginning of the hospice movement in the mid 1960s. In the 1960s and 1970s, caring for people who were terminally ill was quite explicit. Prail (2000) wonders whether the hospice movement is now succumbing to the prevalent view of our death denying society by using terms such as specialist palliative care and palliative care.

Table 1.1: All deaths in Lothian 1989 and 1999

1989		1999	
Hospice deaths	601	Hospice deaths	600
Hospital deaths	5383	Hospital deaths	4825
Home deaths	2394	Home deaths	1918
Nursing Home deaths	306	Nursing Home deaths	1135
TOTAL DEATHS:	8684	TOTAL DEATHS:	8478

However, retention and recruitment of staff in nursing homes is problematic (Redfern et al. 2002). Most care staff in nursing homes are untrained; yet staff are caring for people with complex and multiple diseases with minimal medical advice as GPs find themselves under pressure to give medical cover to nursing homes (Jacobs 2003). There is a danger that nursing homes are seen as an obvious answer to the pressure on hospice beds from older people, but it may not be as straightforward as it first appears (Prail 2000). This thesis helps to illuminate why it is not so straightforward.

This thesis reports on an action research study concerned with the development of high quality end-of-life care in nursing homes. Action research was the research approach that I took on as an integral part of undertaking the project. As a way of my preparing for the action research, I undertook a survey of all independent nursing/dual registered homes across the health authority where the action research was to take place[4]. A 4-page survey on death and dying in nursing homes, adapted from a Department of Health funded study undertaken by Sidell et al. (1997), was sent to the 73 independent/dual registered homes. The questionnaire was divided into three parts requesting information on: the profile of the care home; the number of deaths, diagnosis and place of death; and the professionals involved in caring for dying residents and the palliative care education

---

[4] Not only was this contact a means to understanding more about death and dying in the local nursing/dual registered homes, but it was also a way of informing all nursing homes about the action research study that was to take place following the survey.

given to support this work. There was a 67% response rate for this survey. The majority of nursing homes (90%) had opened within the last 15 years; however, 24% had opened within the last 5 years. A number of the other findings are relevant for this thesis, namely:

- There was an average resident death rate of 34.4% (with a range from 10% - 58.8%) per home for the year 1999.
- In seventeen of the homes the average rate of residents dying in the year was over 40%.
- 55% of residents had died within 2 years of admission.
- The majority of residents had died from multiple pathologies including dementia at the end-of-life. Only 8% of deaths were from a diagnosed cancer.

Apart from familiarising myself with the results of the survey of the 73 independent nursing/dual registered homes, I chose not to do extensive preliminary inquiry or reading about the particular issues of end-of-life care in this setting prior to starting the action research. This was because I wanted to be able to work with staff in the nursing homes in identifying what they felt was problematical and what they wished to develop to overcome the problems. However, more time was spent in understanding how the methodology of action research differed to other approaches and the theory that underpinned it. I therefore went 'into the field' with a theoretical knowledge of action research; but *doing* action research has been an important teacher.

This thesis is written in the first person singular. This is for two reasons. Firstly, self-reflection and critical awareness are an integral part of critical action research – the standpoint that this study takes. Secondly, it is easier to report the collaboration and involvement of those participating in the study namely care assistants, nurses and managers and owners of the nursing homes, by writing in the first person. My historical context was also important, as I became a 'tool' in the development process within the nursing homes. I openly acknowledge that I came to this study as a nurse with a very privileged background in specialist palliative care, having worked at St Christopher's

Hospice, London for four years (1978-1982). With such an exposure to specialist palliative care, I learned how to 'be with' patients and their families facing death. Both Dame Cicely Saunders and Dr Tom West became role models despite being trained in different disciplines. Dame Cicely knew what it was to work within a *multi*disciplinary role; she had personally experienced a career in nursing, as well as in social work and finally medicine. Tom West had the ability to engage in dialogue with a patient as though they were the only two in the room; the conversation would extend way beyond the physical and psycho-social aspects of care, into aspects of spirituality and talking openly about 'how' it was to die. I looked on in awe and learnt. Because of my background, I have undertaken this study in a particular way; someone else without a background in specialist palliative care would have done the study very differently.

1.1 Presentation of Data

Following this introduction, there are seven chapters that make up the body of this thesis followed by a concluding chapter. An outline of each chapter is now given.

Palliative care and nursing homes – Chapter 2

Shakespeare's text from 'As You Like It', quoted at the beginning of this Introductory Chapter, has long been associated more with 'growing old' and 'dying' rather than with scenes of birth, youth and middle age. 'Sans teeth, sans eyes, sans taste, sans everything' portrays a natural if somewhat alarming decline into old age[5]. In Chapter 2, I detail the important role that care homes now play in the end-of-life care of older people as a result of an increasing older population and the closure of NHS long-stay beds. Despite the original principles of geriatric medicine being so akin to those of the modern hospice movement, I consider why it has taken so long for specialist geriatric medicine to grasp the relevance of such principles being aligned to their specialty and therefore to care of older people in nursing homes.

---

[5] Nowadays of course, as a result of better healthcare and medical intervention, much of this is able to be palliated.

The literature on the quality of end-of-life care in nursing homes and in particular that concerned with reforming such care is not extensive. Healthcare professionals in the USA have written much of this literature; however, more recently, important research has come from Australia and the UK. The literature in this chapter is framed using five domains of care highlighted in an important study by Singer et al. (1999) interviewing older people, who were themselves in the last weeks/months of life, being cared for in nursing homes. These domains are important for this study especially in light of the initial exploration of the nursing home context of end-of-life care (Chapter 4). Further discussion about reforming end-of-life care in care homes in the UK draws together results from two major studies – Sidell et al. (1997) and Froggatt (2000a) – published around the time I began the study. Froggatt's (2000a) evaluation study of an educational project that revealed the difficulty care home staff had in changing practice following the palliative care course confirms the appropriateness of the action research approach to this study. Such an approach also contributes to the body of empirical research on end-of-life care in nursing homes most of which has been ethnographic in nature.

Action research as social inquiry – Chapter 3

This chapter introduces action research as a research methodology in nursing. I describe the historical context of action research highlighting its use in organisational change management, education and finally, most recently, in nursing. Because of its varied use, the methodology of action research is associated with a range of epistemological and theoretical perspectives. For the purpose of this thesis, I draw on critical social theorist Habermas, and two of his seminal texts – *Knowledge and Human Interest* (1972) and *The Theory of Communicative Action* (1984, 1987a)[6] – and discuss these in relation to critical action research. I explore reflection as a way not only of learning and gaining knowledge for oneself but also as a way of developing that knowledge and its impacts in

---

[6] There are two volumes to Habermas's Theory of Communicative Action – the first volume (1984) concerns Habermas's thoughts on 'reason and the rationalization of society'. This volume sets up Habermas's further argument of the second volume (1987a) and the importance of the 'lifeworld' and the 'system' within society. Although both volumes address Habermas's Theory of Communicative Action, it is the second volume that is generally referred to in this thesis.

the interests of others (Habermas 1972). I draw on Habermas's arguments in his *Knowledge and Human Interest* (1972) to explicate development of knowledge about end-of-life care through the actions undertaken in this study. Secondly, Habermas's *Theory of Communicative Action* (1987a) is used as a framework to give an interpretation of the major actions undertaken in relation to practice development.

From a standpoint within a critical theoretic paradigm that underpins this action research thesis, I draw on the work of Carr & Kemmis (1986), Kemmis (2001) and McNiff (2002) to support the position I took as an action researcher. Inevitably when undertaking action research as an 'outsider', the politics and power of organisations are tied up with the process of change. Therefore ethics of action research in relation to issues of politics and power, collaboration in the research process, and confidentiality are reported in this chapter.

How the study was conducted - Chapter 4

Chapter 4 describes how I undertook this action research study in collaboration with staff in the nursing homes. I found myself entering a care environment very different from that of the acute hospital setting or the supportive, well staffed, multi-disciplinary care environment of the Hospice. I was also very aware that most residents in the nursing homes were not dying of cancer which is the dominant context elsewhere.

I explain how the nursing home managers/owners 'volunteered' to take part in the study and how the final selection of nursing homes was made; and how what was two nursing homes, became like three different places (NH1, NH2a, NH2b) when the nurse manger in NH2a left. Three phases encompassing the action research cycle, namely: an exploratory phase[7]; a facilitating 'action' phase; and an evaluation phase were undertaken in the nursing homes. During the facilitation phase, the qualitative data, generated as a result of the exploratory phase, were fed-back to staff. As a result, the

---

[7] An exploratory phase did not occur in NH2b as I had already been in the nursing home (under a different nurse manager) for one year.

staff were able to decide how to take things forward. Two major action cycles that helped to develop high quality end-of-life care in the different nursing homes are then outlined: firstly, *the collaborative learning groups*; and secondly, *the implementation of an integrated care pathway for the last days of life.* This chapter provides a detailed description of the different methods used in the generation and analysis of data.

The context of the study nursing homes - Chapter 5

Chapter 5 is the first of three analysis chapters. It provides a detailed analysis of the context of the nursing homes in relation to end-of-life care as a result of data collected during the exploratory phase undertaken in NH1 and NH2a. Context issues that hinder the development of high quality end-of-life care in relation to the management and organisational aspect are highlighted. Clinical issues specific to caring for a resident who is dying are also reported. In both cases, issues are described with the use of direct quotations from both staff and management.

At the end of this chapter, and of the following two analysis chapters, space is given to a reflexive discussion around two key themes – one theme relates to a specific aspect of end-of-life care in nursing homes that was emerging from the data, and the other to a specific aspect of doing action research. Meyer (2000) highlights three aspects of action research that make it a different approach to other methodologies: its participatory nature; its democratic impulse; and its simultaneous contribution to social science and social change. In my reflexive discussions, each of these aspects is highlighted in turn, as they relate to the data respectively in each of the three analysis chapters. In Chapter 5 the key theme about end-of-life care that emerges is that *death and dying appear peripheral to the care in nursing homes.* The key aspect concerned with the process of doing action research is 'participation'[8] – staffs' participation as a result of the exploratory phase and in planning the action cycles.

---

[8] Participation does in fact become a major discussion point later in the thesis when it is reflected on further in the Discussion Chapter (Chapter 8) as a result of uncovering the importance of setting up a 'communicative space' (Kemmis 2001).

Facilitating Change – Chapters 6 & 7

Chapters 6 & 7 present the 'facilitating action' chapters that describe the two major action cycles undertaken in NH1, NH2a and NH2b. The first major action cycle that occurred as a result of the exploratory phase in NH1, and was then continued in NH2a alongside minor action cycles or 'spin-off' cycles (McNiff & Whitehead 2002), was the facilitation of *'collaborative learning groups'*. Chapter 6 describes how these groups were convened in order to develop knowledge and practice in relation to end-of-life care, following the death of a resident in the nursing home. A key point of these groups was facilitating knowledge around end-of-life care through reflection on practice. Ten of these group sessions were tape-recorded. Data from these ten tape-recorded sessions enabled an analysis of the various aspects of care discussed, which highlighted how the *'collaborative learning groups'* were able to facilitate three different kinds of learning – being taught, developing understanding that influences practice, and critically challenging the status quo. The groups encourage appropriate learning through reflecting on practice; furthermore, they also contribute to the supportive and communicative well being of the 'lifeworld' of staff. The second major action cycle, detailed in Chapter 7, occurred as a direct result of the nurse manager in NH2a leaving and staff re-evaluating how they wanted to continue. At this point in the study, it became clear to a number of us in NH2b that one of the issues surrounding end-of-life care in nursing homes was *the lack of anticipating and recognising dying.* As a direct result of this realisation, *'an integrated care pathway for the last days of life'* was introduced. This became a tool used to help organise end-of-life care in the nursing home before a resident died.

Discussion – Chapter 8

This chapter returns to Habermas in order to structure an interpretation of the two major inductively driven action cycles undertaken by staff in the nursing homes. I revisit Habermas's (1987a) *Theory of Communicative Action.* I critically discuss a framework for development of practice around end-of-life care in nursing homes. The framework highlights the concepts of *'lifeworld'* and *'system'* – concepts derived from Habermas's *Theory of Communicative Action,* (1987a) – in relation to the 'collaborative learning groups' and the 'integrated care pathway for the last days of life' respectively. Data from the study are used to strengthen the argument on how the 'collaborative learning groups' developed individual staff member's knowledge of end-of-life care; enhanced collective identity in relation to their care of residents who were dying; and influenced the nursing home culture around death and dying in nursing homes. Further data from the study are also used to illustrate how the 'integrated care pathway for the last days of life' acted as a tool to highlight the importance of end-of-life care within the rehabilitative system of the nursing home; how the tool acted as a *guide* during the last days of life and helped *achieve goals and outcomes* that represent high quality end-of-life care.

Finally in this chapter, I conclude with what I believe is an important lesson I have learnt in relation to *doing* action research. By re-examining my thinking on participation and power in action research, I emphasize the critical importance of dialogue and negotiation between the different levels of practice and management in what is described as a 'communicative space' (Kemmis 2001).

Conclusion – Chapter 9

This chapter concludes the thesis. It considers the extent that aims and objectives of the study were met, and summarises the main findings of the study in relation to the development of high quality end-of-life care in independent nursing homes. It discusses the strengths and limitations of the study. Finally, it highlights policy and practice implications for regulatory bodies of independent nursing homes, the management of nursing home organisations, and the challenge to nurses in leadership within the independent nursing home sector to respond to the important duty that they face in taking greater responsibility for the end-of-life care of older people.

CHAPTER 2

PALLIATIVE CARE AND NURSING HOMES

There is a time to be born and a time to die ***Ecclesiastes 3: 2***

The previous introductory chapter has given an overview of this thesis and outlined how I came to be involved in this action research study. This chapter now discusses the relevant literature in relation to end-of-life care in nursing homes.

Green (2001), undertaking an action research study, began her research with no predetermined idea of any central issue on which to focus her study, in order that actions could be inductively derived with those taking part. Likewise, with this study, I did not do a formal systematic review of the literature related to end-of-life care of older people prior to going into the nursing homes[9]. I was nonetheless familiar with the specialist palliative care knowledge; but, like Green (2001), I wanted to learn from staff who would be participating in this study what they thought were the issues in their context, in order to help bring about relevant change in their practice of end-of-life care. However, a few seminal ethnographic studies on death and dying in nursing and residential homes (Gubrium 1975; Hockey 1990; Shemmings 1996; Counsel and Care 1995) were scrutinised along with an educational study by Froggatt et al. (2000).

Therefore my knowledge of end-of-life care for older people in care homes developed as I accessed the literature during the process of working with staff in the nursing homes. Internet searches that included PubMed, CINAHL, BNI, and NHSe-library were carried out on various subjects (e.g. dementia/palliative care; pain assessment/cognitive

---

[9] A search however was made of the literature concerning action research before and during fieldwork. This is discussed in Chapter 3.

impairment; group reflection/de-briefing; process of dying/old age) throughout the study. However, it is presented in this chapter as a single event. Many times I came across literature by chance that caught my attention incidentally. There were also occasions when friends, interested to know about the study, offered copies of articles that they knew about. One such situation was a non-medical friend whose grandfather gave the Presidential Address to the Leeds and West Riding Medico-Chirurgical Society in 1950. A record of his lecture '*Advancing Years*' (Melvin 1951) was given to me and is cited in this chapter.

It is important to highlight that much of the literature specific to reforming end-of-life care in nursing homes/long-term care facilities has been written since the commencement of this study. Most has been come from North America. More recently, however, further studies have begun to emerge from Australia, the UK and Europe. 'Nursing homes' in North America and Europe differ from those in the UK and Australia. In the UK and Australia, nursing homes are staffed by nurses and untrained care assistants; whereas much of the nursing home research from North America and European countries has been undertaken in large nursing homes where there are often full medical teams and PAM (professionals allied to medicine) teams alongside nurses and their healthcare assistants.

Eighty-one publications were accessed during the study, with the majority (76% of articles) being published in the last five years. Forty-eight of the publications (59%) were research studies. This highlights the current interest in reforming end-of-life care for older people. The accessed literature was catalogued to form ten major categories[10]

---

[10] The literature was categorized under ten original headings with each article catalogued for easy access. The original ten categories were: naturalness of dying in the very old; reforming end-of-life care for older people; implementing palliative care/palliative care approach in nursing homes; the needs of dying residents in care homes including those with advanced dementia; role and support of staff in care homes; doctor involvement and the relationship with nursing homes; hospice movement/geriatrics and palliative care; history of research around death and dying in care homes; legal and ethical anxieties; difficulties associated with care homes as organisations.

that became relevant as a direct result of spending time in the nursing homes. These categories were further reduced to form the main headings of this chapter.

This chapter begins with a brief introduction to the hospice movement and how such a movement arose at a time when geriatric medicine was also emerging as a specialty. Both national (UK and Scottish) and local statistics related to deaths in care homes are then discussed, as well as the way in which care homes have become a place where older people now die (Teno 2003). Section 2.2 discusses the relevance of the naturalness of dying in old age and the importance of good quality end-of-life care for older people cared for in nursing homes/long-term care facilities is highlighted. In Section 2.3, the literature relating to the quality of end-of-life care in the very old is framed by a taxonomy derived from interviews with older people dying in a long-term care facility (Singer et al. 1999). Finally, Section 2.4 highlights research targeted at reforming end-of-life care in care homes. This section highlights some of the difficulties faced in transforming a setting where increasing demands are made on staff, the majority of whom are untrained. It also confirms the need for creative research with innovative solutions aimed at improving end-of-life care in this setting (Oliver et al. 2004).

2.1 THE HOSPICE MOVEMENT AND GERIATRIC MEDICINE

The Hospice Movement that emerged in the mid-1960s as a result of Dame Cicely Saunders work at St Christopher's Hospice, London, has been very successful in promoting specialist palliative 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). As a result of this, the definition of palliative care has become more inclusive of diseases other than cancer:

> *'...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, psychosocial and spiritual.' (Sepulveda et al. 2002:94).*

However, despite its greater inclusiveness, it could be argued that more recent definitions of palliative care are less and less about death and dying directly[11].

When palliative care and geriatrics were both emerging as specialties during the 1970s, considerable similarities could be seen:

> *'Both make the whole person and his or her family the focus of care, while seeking to enhance quality of life and maintain the dignity and autonomy of the individual. Judicious use of investigations are* (sic) *advocated and both eschew unwarranted treatment while providing symptom control and relief of suffering. Both are necessarily multi-disciplinary and both are areas which prompt phobic reactions from society at large. Finally, to carry the parallel still further, in medicine, both Geriatrics and Palliative Care are new medical technologies which challenge the restorative, often aggressive and increasingly technological practices in technological areas of medicine.' (Mount 1989: 97)*

However, whatever Mount (1989) says about the similarities between the two specialties, there are also considerable differences, which might have made the application of the principles of palliative care to gerontology more complex than thought at the time. In the 1950s, the emergence of geriatric medicine as a medical specialty was due to a direct response to the particular health needs of frail older people. Appropriately at that time, the emphasis was on functionality of older people through the rehabilitative process. As a result, the UK is unique in giving acutely ill older people easy access to hospital (Young & Philp 2000). However, this zeal regarding functional rehabilitation may not always sit comfortably with what some might consider the more passive approach in palliative care. Recently, the Royal College of Physicians, the Royal College of Nurses and the British Geriatric Society (RCP/RCN/BGS 2000) published a document setting out the aims of the health and care of older people in care homes. Rehabilitation was seen to underpin the care:

---

[11] In this thesis, 'death and dying' and 'end-of-life care' are used interchangeably; and 'palliative care' is used to represent the longer duration of time represented by the chronic living-dying interval (Engle 1998).

> *'A rehabilitative philosophy of enablement should underpin all care if an older person's potential is to be maximised.' (RCP/RCN/BGS 2000: 8)*

Interestingly in this document, death and dying are absent from its thirty-one pages, and palliative care is only indirectly referred to on two occasions. Although geriatric medicine's founding principles sound very similar to those of palliative care, the rehabilitative emphasis on care and the absence of good quality end-of-life care has become an issue for frail older people in care homes (Hanson et al. 2002).

As a term, 'palliative care' is derived from the Latin verb *palliare*, meaning 'to cloak' (Saunders 1987). Within the hospice movement, where a person has advanced cancer, a palliative approach to care would herald the inability to *cure* the cancer with the subsequent decision instead to treat the symptoms of the cancer along with giving patient and family psycho-social support in preparation for dying. It could be argued that frail older people in their 80s and 90s are at the 'end of their life'. At that age one is approaching death; there is not the same necessity to 'cloak' the reason for no cure – this *is* old age. But because there is no direct decision to change the emphasis on treatment, frail older people both with and without a cancer diagnosis do not routinely receive 'palliative care', whether in a long-term facility, a nursing home or at home (Reynolds et al. 2002; Mitchell et al. 2004a/b). Without any decision to change the emphasis, symptoms are in danger of being left untreated (Lloyd-Williams & Payne 2002).

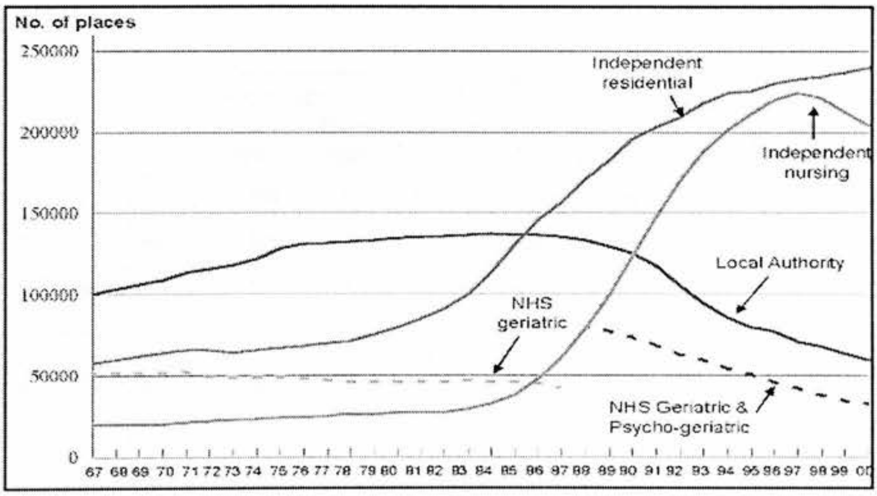
Despite the emergence of these specialties at the same time, with what appeared similar philosophies, it has taken over fifty years for many geriatricians to realise the importance of palliative care for their population. Emanuel (2004: xi-xii) highlights that *'fears of older people being discarded as ineligible for medical interventions may have underla[in] some early reluctance to accept palliative care into geriatrics'*. Medical intervention is appropriate for those very old people for whom such an intervention will improve the quality of life. But for those with multiple medical pathologies who are frail and require 24-hour care, a palliative approach to care is likely to be more appropriate.

With the future direction of geriatric medicine moving away from acute hospitals to the community (Young & Philp 2000), questions about appropriate intervention, quality of life and end-of-life care are being raised. An important part of this discussion is the need to consider high quality end-of-life care; by this I mean death and dying in care homes.

2.1.1 Care homes as places where older people die

As a result of the Griffiths Report in the 1980s and the NHS and Community Care Act in 1990, an increased amount of care for older people has been transferred to the community. With the subsequent closure of long-stay geriatric wards alongside an increasing ageing population, independent care homes have now become the key places where frail older people are cared for (see Fig.2.1).

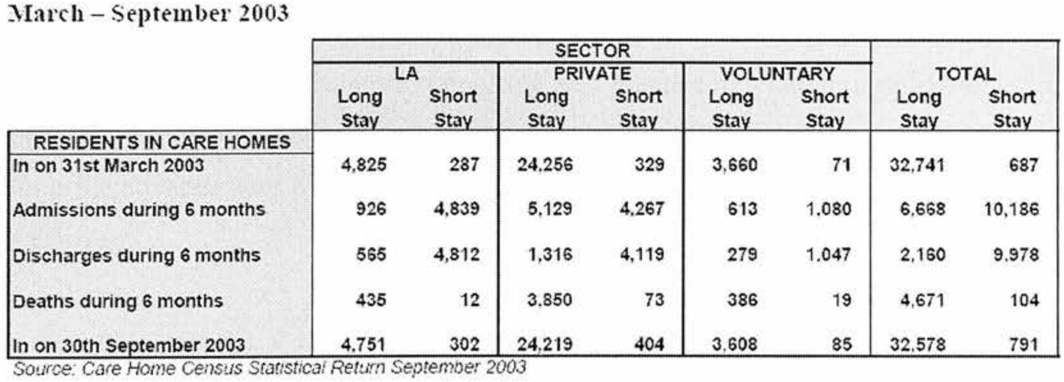
Fig. 2.1: Nursing and residential care places for elderly, chronically ill and physically disabled, by sector, UK, April 1967-2000 (Laing & Buisson, 2002)



In 2004 the population of the UK was 59.8 million. During that year, there were a total of 570,437 deaths, of which nearly 60% were over the age of 75 years (National Statistics Online 2004). One fifth of deaths in people over the age of 65 years in the UK occur in care homes (Teno 2003; NCPC 2005). It is true that people are living longer in their own homes, having their community care needs met by social services; but when they are admitted to a care home, their condition is consequently frailer and their length of stay shorter than before 1990. A majority of the deaths of residents in nursing homes die within two years of admission (Sidell et al. 1997; Hockley et al. 2004).

In Scotland in September 2003, there were 979 care homes for older people (Scottish Executive 2003). The number of occupied places (36,777) for older people varies but in the census for September 2003, there were 33,369 older people in care homes (see Fig. 2.2). Fig. 2.2 shows figures for the 6-month period March-September 2003. During this period there were 4,775 deaths. Even though doubling this figure for the year is likely to be *underestimating* the percentage of deaths because it does not include the winter months, the average annual rate of residents dying in care homes across Scotland amounts to 32%.

Fig. 2.2: Number of Admissions, Discharge and Deaths in Homes for Older People
(Scottish Executive 2003)



March – September 2003

	SECTOR							
	LA		PRIVATE		VOLUNTARY		TOTAL	
	Long Stay	Short Stay	Long Stay	Short Stay	Long Stay	Short Stay	Long Stay	Short Stay
RESIDENTS IN CARE HOMES								
In on 31st March 2003	4,825	287	24,256	329	3,660	71	32,741	687
Admissions during 6 months	926	4,839	5,129	4,267	613	1,080	6,668	10,186
Discharges during 6 months	565	4,812	1,316	4,119	279	1,047	2,160	9,978
Deaths during 6 months	435	12	3,850	73	386	19	4,671	104
In on 30th September 2003	4,751	302	24,219	404	3,608	85	32,578	791

Source: Care Home Census Statistical Return September 2003

In 2001, there were 1,076 deaths of residents in nursing homes across the health authority where this study was undertaken. This accounted for nearly a third (31%) of the total number of the 3,700 nursing home beds[12] confirming national statistics in the previous paragraph.

---

[12] This figure is 95% of the total number of beds in order to account for lack of occupancy

Palliative and end-of-life care guidelines for older people

During the past five years, the need to set guidelines for the palliative and end-of-life care of older people in care homes has been recognised. Fisher, Ross & MacLean (2000), from the University of Toronto, were the first to produce *A Guide to End-of-Life Care for Seniors*. An interdisciplinary team of palliative care professionals and geriatricians clarified terminology around end-of-life care, palliative care and geriatric care. In integrating philosophies and principles of practice across palliative care and geriatrics, they defined end-of-life care for seniors as requiring:

> *'...an active, compassionate approach that treats, comforts and supports older individuals who are living with, or dying from, progressive or chronic life-threatening conditions. Such care is sensitive to personal, cultural and spiritual values, beliefs and practices and encompasses support for families and friends up to and including the period of bereavement.' (Fisher et al. 2000: 9)*

In Australia, a working party hosted by the Edith Cowan University have comprehensively addressed *Guidelines for a Palliative Approach in Residential Aged Care* (The National Palliative Care Program 2004). Within the guidelines, there is a systematic review of the literature supporting best practice in relation to residential care. Assessment tools to identify pain and other symptoms, quality of life etc. are included alongside advance care planning, examples of advance directive documents and power of attorney.

In the UK, general Care Homes Standards have been set and are regulated by commissioners on a yearly basis. One of the standards relates to 'death and dying'. However, despite a third of residents dying in nursing homes each year, this specific standard may not necessarily be audited by the regulators[13] every year (personal communication, Care Communication 2004). As a result, the Scottish Executive has commissioned a document (SPPC 2005) that highlights the importance of palliative care across *all* care home standards. The document emphasizes the importance of a palliative

---

[13] Some researchers doubt the effectiveness of the regulation of care by an external body (Forbes-Thompson & Gessert 2005). Regulators can be seen as having a 'policing' effect that just maintains the status quo rather than encouraging creative ideas and improvements in care.

approach to care in care homes in line with what is being currently advocated in the literature (Katz & Peace 2003; Kristjanson et al. 2005; Kayser-Jones et al. 2005). As a result of these palliative care statements, every care home, whether it offers 24-hour nursing care or personal care only, will be regulated alongside these practice statements to ensure 'good' palliative care. For those nursing homes who want to 'specialise' in giving high quality palliative/end-of-life care for people with more complex end-of-life needs, the document sets out 'best practice' statements by which a care home can be regulated.

Identification and assessment are being seen as important aspects of better management of symptoms for older people in nursing/care homes (Parker & McLeod 2002). The lack of a rigorous unified assessment of older people in UK care homes has been highlighted (RCP/RCN/BGS 2000; NCPC 2005). A number of countries including USA, Australia, Iceland and Denmark use a Minimum Data Set (MDS) that records aspects of a resident's mobility, symptom control, and psychosocial care on a monthly basis. From these assessments, a large number of studies have been able to identify the degree of distress of older people at the end-of-life in care homes (Buchanan et al. 2004; Mitchell et al. 2004b; Bernabei et al. 1998). However, there is some evidence that such an assessment tool is inappropriate in palliative care and needs revision (Forbes et al. 2000; Buchanan et al 2004). A recent study (Dunckley et al. 2005) in the UK has tested the usefulness of the POS (Palliative Care Outcome Scale) assessment tool in care homes.

It remains to be seen how such policies/guidelines influence practice. Such documents can be large and unwieldy with subsequent benefits only for those involved in compiling them rather than for those people for whom they were intended. Policies/guidelines are placed in libraries, even sent to care homes, but often do not bring about change without further strategic development being promoted in practice.

2.2 NATURALNESS OF DYING IN OLDER PEOPLE AT THE END OF LIFE

In today's modern society, dying as 'a natural, final event' in old age has been usurped by technologies now available to maintain life at any cost (McCue 1995: 1039). Maintaining life for a particular reason and in discussion with the person concerned is appropriate. However, when life is prolonged inappropriately, the dignity assigned to dying in old age by Melvin (1951) is not easy to achieve:

> *'It is in accordance with nature for old men to die and "their dying is a quiet withering, a cooling of the embers." By comparison death in youth is a violent episode, powerfully resisted and opposed by nature. It is a furious conflagration.' (Melvin, 1951)*

The use of life-support machines, tube-feeding, and repeated treatment of pneumonia ('the old man's friend') with antibiotics (with little concern as to its appropriateness and lack of discussion with the patient/resident, staff or family) can rob older people of a more peaceful 'cooling of the embers'. In a large study of nursing homes in the USA (n = 63,101) it was reported that 34% of residents with advanced cognitive impairment had feeding tubes (Mitchell et al. 2003).

It would appear that dying without inappropriate prolongation is as difficult a concept to grasp for families as it is for physicians. Forbes et al. (2000), in their focus group research involving family members of residents suffering from advanced dementia, discussed how family members did not want to prolong dying or cause undue suffering; they wanted a 'natural' death for their relative. However, when it came to those in the focus groups describing the likely events of a 'natural' death for their frail relative, and how it might occur, they were unable to do so. There was considerable difference between participants' *talking* about the 'naturalness of dying in old age' and their *understanding* of it; how it occurs and how it is achieved. The technologies current in modern healthcare are often used to prolong the life of a frail older person in a care home because of a lack of open discussion and knowledge about alternatives.

In the literature on end-of-life care in nursing homes, the word 'frail' and 'frailty' is regularly used as a euphemism to describe a resident's deteriorating condition. The image of nursing homes as places where older people admit themselves to seek companionship in the latter years of life has changed. Residents admitted for 24-hour nursing care are now already unable to do many of the activities for daily living on their own and a majority require two people to help them. Lynne & Adamson (2003: 4) define 'frailty' in an older person in a nursing home as 'a fatal chronic condition in which all of the body's systems have little reserve and small upsets cause cascading health problems.' It is this meaning that is adopted for this study.

Even though a majority of frail older people have definite medical diagnoses associated with their deteriorating condition, some do not. McCue (1995) describes three case studies of very old people (one lady reaching 109 years old before she died) who had lived a number of years in an aged-care facility in the USA and then died naturally from old age. All had routine laboratory tests carried out alongside yearly physical examinations and died without an identifiable chronic or acute illness. These declines are as 'natural in advanced age, as growth and development are in the healthy young person' (McCue 1995: 1039). He stresses the importance of recognising 'natural' dying. In these three cases, no disease morbidities were found on post-mortem. On reviewing the cases, McCue (1995) states that natural dying occurred as a result of the person gradually losing interest in eating and then drinking which in turn heralded a short dying phase. When life has been lived to the full and the 'right time' comes, nothing can be more respectful than *allowing* a person to die:

> *'Respect for the wholeness of life requires that we not debase its final stage: art, literature, and the social sciences teach us that a good death can be a natural, courageous, and thoughtful end to life.' (McCue 1995: 1039)*

Care home residents are not ignorant of their fate. In interviews with older people, death has been addressed as 'an inevitable completion of the life circle (sic), a phenomenon that one has to accept since it cannot be avoided or overcome' (Leichtentritt & Rettig 2000:

228). Yet often frail older people in care homes are 'protected' from a death when it occurs (Katz & Peace 2003).

Many older people, whether in long-term care facilities or care homes, are only too aware of death. Gubrium (1975) in her seminal ethnographic study of *Living and Dying at Murray Manor*, reports that residents live with the knowledge that dying and death are imminent events for them. Professor Philp (2003) highlighted this when he visited a sheltered housing complex. He reported how the oldest resident took him to see a plaque that had been put up in the conservatory with the name of everyone who had lived and died in the home. The resident is reported as saying, *'we are old, we know we are going to die, and might die quite soon. We are just so fortunate this is the place where we are going to die ...'* (p.151). It is important that the living/dying interval (Pattison 1977) – a time between the knowledge of one's impending death and death itself – is acknowledged. Such a time can be usefully deployed to encourage appropriate advance care planning in order to promote dying as a natural part of the life cycle in those very old people who require 24-hour nursing home care.

2.3 QUALITY OF END-OF-LIFE CARE IN NURSING HOMES

Descriptions of and principles for quality end-of-life care, and the tools to measure it, are used extensively in palliative care (Emanual & Emanual 1998; Field et al. 1997; AGS 1997; DoH 2001). Whether these principles are for specialist palliative care or the palliative care needs of older people without cancer, for the most part they have been drawn from focus groups with family members, health care professionals or expert panels rather than from patients themselves. Age Concern (1999) has drawn up 12 principles[14] for what they believe constitutes a 'good death', based around control,

---

[14] Twelve principles for a 'good death' drawn up by Age Concern (1999):

- To know when death is coming, and to understand what can be expected
- To be able to retain control of what happens
- To be afforded dignity and privacy
- To have control over pain relief and other symptom control
- To have choice and control over where death occurs (at home or elsewhere) [continued on pg.23]

autonomy and independence. It is a lengthy list which is not easily remembered when trying to put such principles into practice within the context of a busy care home.

Brazil et al. (2004), in their study of seventy-nine direct care providers of six long-term facilities, derived six themes that contribute to quality end-of-life care, namely: responding to resident needs; creating a homelike environment; providing support for families; providing high quality care processes; recognising death as a significant event; having sufficient institutional resources. Many of these themes are quite ill defined, with at least half being about the nursing home as an organisation in general which might only indirectly involve the care necessary for dying residents. Probably the most important theme is 'recognising death as a significant event', without which good quality end-of-life care would be impossible. Hanson et al. (2002) are more specific about what staff described as barriers to high quality care of the dying: namely, a lack of palliative care training; a regulatory emphasis on rehabilitation; and a lack of sufficient staff.

There were two studies that actually interviewed frail older people themselves, living in a nursing home or aged-care facilities, about quality end-of-life care. One study was by Forbes (2001) who interviewed thirteen residents as part of a wider organisational project in nursing homes. Forbes's (2001) study highlights the calm acceptance of death by frail older people in a nursing home but reports that the actual process of dying 'was described by both staff and residents as cold, lonely and painful' (p.41). A larger study was by Singer et al. (1999). I became very interested in the qualitative study by Singer et al. (1999) early in the fieldwork of this study. They interviewed 126 patients about

---

[continued from footnote on pg.22]

- To have access to information and expertise of whatever kind is necessary
- To have access to any spiritual or emotional support required
- To have access to hospice care in any location, not only in hospital
- To have control over who is present and who shares the end
- To be able to issue advance directives which ensure wishes are respected
- To have time to say goodbye, and control over other aspects of timing
- To be able to leave when it is time to go, and not to have life prolonged pointlessly

control at the end-of-life, and as a result, through analysis of the qualitative data, came up with a taxonomy that was simpler, more straightforward and more specific than others and one that was 'homogeneously focused on outcomes rather than processes of care' (Singer et al. 1999: p.166). The patients, all of whom had life-threatening conditions, were drawn from three different cohorts. It is the results of thirty-eight patients from the cohort of people from a long-term care facility that are of relevance to this study, and from which Singer et al (1999) derived a taxonomy of high quality of end-of-life care, forming five domains (see Box 2:1).

Box 2.1 Singer et al. (1999) 'Taxonomy of Quality End-of-Life Care'

Five domains that older people report contribute to quality end-of-life care (Singer et al. 1999):

- avoiding inappropriate prolongation of dying
- relieving the burden
- achieving a sense of control
- receiving adequate pain and symptom management
- strengthening relationships with loved ones

These five domains from the Singer study are comprehensive. All the twelve principles drawn up by Age Concern (1999)[15] fit within the Singer taxonomy. Their taxonomy is altogether easier to remember for healthcare professionals involved in the everyday clinical work with residents/patients. Its legitimacy is enhanced when one considers that the domains come directly from discussions with frail older patients being cared for in an aged care facility.

For the purpose of discussing the wider literature concerning quality end-of-life care in nursing homes in this section, I have adapted the five domains from the Singer et al. (1999) taxonomy. Two of the domains ('avoiding inappropriate prolongation of life' and 'relieving the burden') have been joined as 'end-of-life decision-making'; the rest remain the same. Although 'end-of-life decision-making' is a more technical title than

---

[15] For the twelve principles drawn up by Age Concern see the footnote on pg. 22/23 in this thesis.

those suggested by Singer et al., the importance of advance care planning (Hanson et al. 2002) in anticipating dying is highlighted. In the case of frail older people, such planning of appropriate thought-through care helps to avoid inappropriate prolongation of life. Many frail older people requiring 24-hour nursing care speak openly about their concern not to become a burden. In Howarth's (1998) study looking at the quality of life for people over the age of 75 years who were still relatively well and living in their own homes, 58% of participants made some mention of death. 62% of these people were concerned about not becoming a 'burden', especially in relation to their thoughts of a slow, lingering death. End-of-life decision-making is thus seen as an appropriate domain to accommodate both relieving the burden and avoiding the inappropriate prolongation of life.

2.3.1 End-of-life decision-making

In nursing homes there are a number of issues that complicate end-of-life decision-making. One of these is the high proportion of residents with varying degrees of dementia (Katz & Peace 2003). This can complicate communication about end-of-life decision-making, especially if residents' wishes about treatment to prolong life are not documented or not known. There is considerable discussion in the literature about the right time to have such discussions (Reed et al. 2002). Many nursing home organisations, especially in the USA, would insist that advance directives are discussed and completed on admission to a nursing home. However, it has been shown that the writing of an advance directive, as a result of compliance with institutional standards, does not necessarily translate into improved decision-making around death and dying (Happ et al. 2002; Lynn & Goldstein 2003). If care staff want to individualise their care of residents then perhaps there is no set time, the right time being when it is right for each individual resident. Others (Strumf et al. 2004) suggest that such conversations should be on-going. However, research (Vallis & Boyd 2002) carried out in Scotland suggests that many care home staff find it difficult to talk about end-of-life care and prefer to avoid such discussions if at all possible. The situation is complicated still further when staff in nursing homes, including managers, do not acknowledge advanced dementia to be a terminal condition (Mitchell et al. 2004b; Morrison & Siu 2000). Many staff perceive dementia as a 'social' problem, rather than understanding it as a disease that progresses like any other disease and therefore needs palliation in its advanced stages. When eating and drinking difficulties progress to increasing weakness, poor mobility and recurrent pneumonia heralding the end stage of dementia, further treatment can only prolong a life that is radically reduced in its quality.

In many western societies, a person's experience of a family member dying often occurs much later in life and as a result many people do not talk about dying or know what to expect. In the study by Forbes et al. (2000), family members of nursing home residents with advanced dementia participated in focus groups to share end-of-life decision-making experiences. The majority of those taking part had imagined that dying would occur suddenly as in a heart attack or a stroke.

> *'The need for active involvement of health professionals in initiating and guiding advance care planning was clear ...' (Forbes et al. 2000: 257)*

Forbes et al. (2000) concluded '*we had assumed that most of the participants would be accepting of the fact that dying was ongoing and would be able to share their decision-making experiences with us. We were wrong' (p.256).* Their research highlights the importance, and difficulty, of advance care planning by health professionals around death and dying in a population where end-of-life decision-making can be complicated by a 'dying trajectory' that is often 'unrecognised' and 'disguised'.

The trajectory of the dying process of differing diseases has been described by Lynn & Adamson (2003). The 'dwindling dying trajectory' (Lynn & Adamson 2003) associated with the deterioration of frail older people adds to the difficulty of being able to come to a decision about dying. Such a gradual, slow decline makes it difficult to distinguish between what is a 'blip' in the condition of a frail older resident/patient and what actually indicates the beginning of the dying process. Some fifteen years ago, Cowley (1990) described the 'slow' dying of chronically ill patients as a particular difficulty for community nurses to cope with. She too highlighted that it was both 'the fact' and the 'duration' of dying that district nurses found difficult.

Flaming (2000) suggests that the only way to improve the quality of end-of-life care in care homes, a quality that includes appropriate communication and symptom control, requires that the dying resident be labelled as 'dying' in anticipation of the event. This may sound harsh but Flaming grasps an important fact about end-of-life care: if staff are unable to talk about death and dying amongst themselves, it is likely that appropriate preparation will not be made and that residents will not be given the opportunity to speak about dying when the appropriate time presents itself. He suggests that labelling 'dying' should be done both verbally amongst staff and formally through written communication in the care plan. Forbes (2001)[16] also takes up the theme of the importance of 'labelling'.

> *'The inability to label someone as terminal disguised dying and resulted in a lack of communication regarding individual needs and personal preference. This was confirmed by observing day-to-day practices and MDS+ care planning conferences……The work environment, influenced by the MDS+ care planning process, created a focus on preserving and promoting functional status. This care planning assessment tool lacks the language and triggers for palliative care planning, thus decreasing the opportunity for communication regarding end-of-life treatment preferences.' (Forbes 2001:43)*

In the large nursing home where Forbes's study was undertaken, an audit tool (MDS+) that is used widely in the USA and in certain areas in the UK, was found to *decrease* the chance to enhance the quality of end-of-life care. The inability to highlight that a resident was terminally ill because of the 'rehabilitative' emphasis of the documentation being used, meant that staff were reluctant to confirm that someone was dying unless death was imminent. Because of this emphasis on rehabilitation in care homes (Hanson et al. 2002; Travis et al. 2002), many nursing home staff (both trained and untrained) have never been shown how to recognise dying (Katz et al. 1999). The obscuring of the

---

[16] The MDS+ is a 'minimum data set' audit tool that is routinely completed when a person is admitted to a nursing home in the USA. It is completed on admission and then yearly in order to assess a resident's functional/symptom status. It has 300 items in 20 assessment domains. Completion takes approximately 30 minutes by an experienced person (Parker & McLeod 2002).

importance of recognising dying because of rehabilitation is not a new phenomenon. Graham & Livesley (1983) reported it as an issue in their study based on interviews with staff in a long-stay hospital:

> *'The active rehabilitative approach to patient care within modern geriatric medical units may make it difficult for staff to change from the curing to the caring mode.' (Graham & Livesley 1983: 671)*

Many nurses in nursing homes see making the change from cure to care as the GP's responsibility rather than a joint decision between staff in the home, family and even the residents themselves. In the UK, where there is little regular GP contact time in the majority of nursing homes unless a contractual fee is paid (Jacobs 2003; Glendinning et al. 2002), there is a danger that the duty of diagnosing dying falls to a locum/on-call physician who does not know the resident. In such a situation there is a tendency to take resuscitative measures (even if these involve *only* antibiotics) until the patient's own doctor is able to visit. Blackburn (1989) suggests that it is an experienced nurse who is most likely to be the first to recognise when an elderly patient is dying, not the doctor. If nurses do not want to take on this responsibility, high quality end-of-life care may be more a case of chance than of judgement.

The fear of litigation in the USA has increased defensive practice concerning active end-of-life decision-making in nursing homes (Kapp 2003; Bottrell et al. 2003). Although this is not such an issue in the UK, the Shipman inquiry (Shipman Inquiry 2005) might nonetheless potentially compromise good end-of-life care practice. As a result of Shipman's crimes, GPs with high mortality rates of patients are now scrutinised (Mohammed et al. 2004) and nursing home regulators also 'check out' practice in nursing homes where a 'higher than usual' percentage of residents have died. The added emphasis that both regulators and organisations put on 'rehabilitation', with little recognition that the majority of residents die within two years of admission to a nursing home (Sidell et al. 1997), further complicates this.

Not being aware that a resident is dying, or deliberately denying such a situation, can have considerable adverse effects on respecting a resident's desire to have a sense of control about the end-of-life and the control of symptoms in the last days of life. These are the subjects of the next two sections.

2.3.2 Achieving a sense of control

To be in control of a situation demands that one is knowledgeable of the facts surrounding that situation. When faced with the last days/weeks of one's life, opportunity to talk is often restricted even by those who care. Tolstoy's (1960) famous short story, *The Death of Ivan Ilyich,* poignantly stresses the importance in most situations of talking openly about dying in order that the person herself or himself feels involved and not isolated:

> *'What tormented Ivan Ilyich most was the deception, the lie, which for some reason they all kept up, that he was merely ill and not dying, and that he only need stay quiet and carry out the doctor's orders, and then some great change for the better would result. But he knew that whatever they might do nothing would come of it except still more agonizing suffering and death. And the pretence made him wretched: it tormented him that they refused to admit what they knew and he knew to be a fact, but persisted in lying to him concerning his terrible condition, and wanted him and forced him to be a party to the lie.' (Tolstoy 1960: p.142-3)*

Tolstoy graphically describes the deceit undertaken in not telling Ivan that he is dying. Ivan himself knows the inevitable. To some extent one might possibly understand the tension and difficulty of acknowledging a terminal illness when life is being cut short from cancer. However, as reported in section 1.2, many older people in care homes are ready to acknowledge that their lives are drawing to a close. This is not to say it is any less profound or any easier for residents, but there is generally a greater openness in their minds to address it. Forbes (2001) found that residents were willing to discuss death and dying but this was not addressed by staff:

> *'Residents were comfortable talking about death, but noted that staff did not initiate discussions regarding death. An interviewer asked, "Does the staff know that you are ready?" The resident responded, "I don't know, they don't ask, but my roommate and I, we talk about these things."' (Forbes 2001: 42)*

An ill person, who strongly suspects that he is dying, but is denied the least opportunity to question or discuss it, can feel cruelly isolated. Like Ivan Ilyich, many residents are aware of the artificiality of deception. In a seminal study undertaken by Exton-Smith (1960), staff reported that seven of the 'aged' patients interviewed about their end-of-life needs, had had a premonition of death within a few hours/days of their death.

Katz et al. (2000) discovered an anomaly between, on the one hand, the acknowledgement by nursing home managers that residents are quite philosophical about the fact that they will die at some point, and yet on the other, the secrecy with which death is dealt with in many nursing home organisations:

> *'Despite the fact that home managers maintained that residents were philosophical and accepting of death, the practice of concealing death from residents was wide-spread.' (Katz et al. 2000: 275)*

Peer pressure and not wanting to admit failure remain dominant reasons for the lack of openness amongst staff about death and dying (Flaming 2000). This persistence of remaining hopeful in a 'closed awareness' culture of dying (Glaser & Strauss 1965) just compounds the difficulty for residents who would like to take control and talk about dying. Labelling dying earlier than the immediate point of death not only gives permission for the resident and family to spend important time together for private and public rituals (Flaming 2000), but also enables staff to plan necessary care for the last days of life.

2.3.3 Pain and symptom control

Many older people fear the process of dying more than actual death itself (Emanuel 2004). Although dying itself is not painful, nonetheless pain is a major issue for many residents in nursing homes (Bernabei et al. 1998; Ferrell et al. 1995; Katz & Peace 2003). Cook et al. (1999) highlight that the reporting habits of older people make pain control more difficult to assess. Many older people believe pain to be something they have to 'put up with' as part of growing old and unless older people complain of pain it is often not detected. Froggatt et al. (2000) highlight that there are three aspects of pain control for older people in care homes that differ significantly from experience in specialist palliative care. The client group is different, the pain picture is different and the assessment process is different. Residents in care homes have multiple chronic conditions and many also have communication difficulties, especially in the case of residents with dementia. Only a small percentage of people in care homes have cancer (Katz & Peace 2003; Hall et al. 2002); instead, pain is mainly related to musculoskeletal problems and neuropathies (Weiner & Hanlon 2001). The lack of validated and reliable assessment tools for people with dementia means that pain may not be assessed adequately, in which case it is likely that it is not being managed appropriately. Poorly treated pain is associated with increased risk of disability and depression (Frampton 2003).

Nursing home staff's understanding of pain and its management in older people is less comprehensive than that of trained nurses working with older people in the NHS (Gibbs 1995). In Gibbs's study, those working in nursing homes were as passionate about caring for dying residents, but their knowledge of pain control and opportunity for education in this area of care was severely limited compared to trained nurses working with older people in NHS wards.

It is also widely reported that the control of symptoms other than pain is generally poor for residents in nursing homes (Mitchell et al. 2004b; Reynolds et al. 2002; Hall et al. 2002). In a recent study of the last 48 hours of residents dying in a long-term facility in Canada (Hall et al. 2002), 49% of residents never had their noisy breathing treated, 38% remained delirious, and 23% were not treated for their breathlessness. In light of this research, residents' fear of inadequate pain and symptom management is likely to be founded on the reality of experience or what they have witnessed.

The importance of having time to plan end-of-life care is particularly important in nursing homes in the UK. Unlike North America and Europe, nursing homes in the UK do not have medical personnel included as part of the organisation. Nursing home managers are therefore not allowed legally to keep medication used for end-of-life care as a 'stock' medication. Medication to control symptoms in the last days of life must therefore be ordered individually for each resident. If dying is not recognised until death is imminent, symptoms will not get treated. Anticipating and labelling dying is therefore important; without such labelling many aspects of quality end-of-life care are at risk of not being attended to with the resident being the person who suffers most.

2.3.4 Strengthening relationships with loved ones

The final domain, in the study by Singer et al. (1999), which participants said contributed to high quality end-of-life care was the importance of strengthening important relationships in the last weeks/days of life. In the study by Forbes et al. (2000), family members reported that the lack of consistent communication and not being prepared for the death or dying of their loved ones meant they lost the opportunity to spend important time with relatives who were dying. Some of the reasons that hampered participants' communication related to organisational issues such as the frequent turnover of nursing staff. Participants reported that most information regarding the care of their loved ones came from untrained nurse aides. Although overcoming difficulties in speaking about dying is not easy, opportunity to speak about death and dying was of 'overwhelming importance' to residents in the study by Singer et al. (1999). These authors also challenge the current approach to end-of-life decision-making that underestimates the importance of the residents' social and family context, and focuses on just the individual resident herself or himself.

But what happens if residents in nursing homes do not have family who visit regularly? Moss et al. (2003) in their research found that staff in nursing homes used a metaphor of 'family' to describe their own involvement with residents who were dying. Through viewing residents as 'family', caregivers found that care giving became more meaningful, and the institutional 'distance' between resident and staff lessened. The length of stay of many residents in care homes enables care assistants to become more involved than in other settings. Some staff would come in to the nursing home on their 'days off' to sit with a dying resident, especially if that person had no family, in order that the resident was not alone. The relationship that staff had with residents was likened to that with their own family, but not with the same degree of involvement. The researchers found that staff spontaneously told stories of family deaths and how such a death had helped them care more compassionately for residents in the nursing home. Having such a relationship with residents and using the metaphor 'family' was felt to help compensate for the lack of power that many staff felt residents had within the home.

Although an increasing amount of 'end-of-life care' research is now being carried out in nursing homes, little of the research has brought about any change in care. Reforming end-of-life care in care homes is a major issue if older people are to die with their symptoms controlled, and both their and their families' emotional and spiritual needs duly met.

2.4 REFORMING END-OF-LIFE CARE IN CARE HOMES

There is a growing body of research describing concern over the quality of palliative and end-of-life care for older people in care homes and aged-care facilities, as discussed in the previous section. However, there is also concern in the literature about organisational issues in nursing homes. Low morale, and poor retention and recruitment of staff are endemic in care homes/long-term care facilities across western societies (Redfern et al. 2002; Sidell et al. 1997; Maddocks & Parker 2001; Kristjanson et al. 2005; Forbes 2001). Recent research highlights that such organisational issues within nursing homes influence negatively the quality of care given (Anderson et al 2004; Castle & Engberg 2005). It is unsurprising that Komaromy et al. (2000), in a survey of 1,000 care homes, reported that 21% of care home managers who responded maintained that staff shortages affected adversely the care given to residents who were terminally ill. With added issues of an increasing number of deaths in nursing homes, lack of appropriate knowledge of palliative care, lack of support of staff, and lack of adequate supervision (Teno 2003;

Katz & Peace 2003; Rice et al. 2005), it could be argued that nursing homes unwittingly conceal considerable suffering not only for residents but also for staff. When independent care homes took on the work of caring for older people as a result of the NHS and the Community Care Act in 1990, it is likely that they did not realise what an important burden they were being asked to shoulder concerning end-of-life care. The difficulties of now trying to work with these shortcomings in the light of financial and staffing restraints make the development of high quality end-of-life care complex.

A Department of Health study undertaken by Sidell et al. (1997) demonstrated that most care homes in England were isolated from palliative care education/training, much of which was available to health professionals within the NHS. This large study that began in 1995 was carried out by a team from the Open University, UK and has been widely reported (Katz et al. 1999; Katz et al. 2000; Komaromy et al. 2000; Katz & Peace 2003). It used a multi-methods approach covering three stages. The first stage was an overview of care homes as a setting for older people who were terminally ill (survey to 1000 residential, nursing and dual-registered homes – 41% response rate). The next stage interviewed managers from 100 care homes sampled from those responding to the first stage; interviews covered a variety of issues affecting palliative/end-of-life care and included staffing arrangements and training in palliative care. The final stage was an ethnographic study (including participant observation, informal and tape recorded interviews) to examine how death and dying was managed in twelve of the care homes.

The study highlighted the fact that scarcity of resources of both staff and equipment affected the quality of terminal care in the care homes. The team commented on the rigid hierarchy of the majority of homes that contradicted the attempt of many managers to make the care homes 'homely'. As in other studies (Burack & Chichen 2001; Hall et al. 2002), the researchers found many care assistants very committed to their work with dying residents. However, it was identified that many staff had little support from management in coping with death and dying.

Although Sidell et al. (1997) reported that the 'heads of home' set the standard of care for residents, only 8% of managers both understood the principles of palliative care and thought them relevant. Over two-thirds of managers were unfamiliar with the term 'palliative care' and 'hospice philosophy'. As well as recommending better support from GPs, adequate staffing ratios to accommodate the sudden change in a resident's condition, palliative care education and training, and more adequate resources (Komaromy et al. 2000), the report recommends that specialist palliative care input for nursing homes should be available from local specialist palliative care/hospice services (Katz et al. 1999). However, one problem with such a recommendation is that it assumes a degree of palliative care knowledge within nursing homes, as a basis for recognising specific problems for consultation. It also assumes that specialist palliative care services have enough staff to be able to take on the support of nursing homes.

Froggatt & Hoult (2001) surveyed 730 community palliative care nurse specialists and their involvement with care homes. They found that much of the work being undertaken by community specialist palliative care teams was reactive, with little proactive work being undertaken to improve end-of-life care practice. The work was also primarily with cancer patients and not residents suffering from other diseases. The community palliative care nurse specialists identified three factors that occurred both within their own practice and that of care homes, which negatively affected their ability to promote palliative care more systematically in care homes: staffing, resources and management. Such context issues play a substantial barrier to high quality end-of-life care for their residents. Swagerty et al. (2005) in their research of three Midwestern nursing homes in the USA also found that good end-of-life care planning was fragmented by context issues such as competing demands on staff time, and a hierarchical, task orientation to care.

In the UK, as a result of an increasing number of care homes being built, 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, get appropriate medical care and how GPs are sufficiently reimbursed for their care (Jacobs 2003; Carlisle 1999; Groom et al. 2000). In the past, patients on long-stay geriatric wards had access to a doctor specialising in geriatric medicine. Although long-stay geriatric wards were far from ideal, patients were at least reviewed on a daily basis where necessary. With the majority of older people now cared for in care homes, this can be an impossible task for a GP especially if there are a number of care homes in the practice area. Nursing homes are associated with higher workload for GPs (Groom et al. 2000). Some GPs receive reimbursement from nursing home managers to visit up to three times a week (Glendinning et al. 2002) in order to pay for the extra service. This raises questions about equity of medical access for those residents in nursing homes whose management do not provide such reimbursement. Increasingly, it is the nurse in the care home who has unwittingly taken on what in the past has been the role of junior doctors: namely, the day-to-day observation of a resident's condition. The implications that this might have, not only for residents but also for the care environment, add to the concern about quality end-of-life care in this setting without appropriate practice development.

2.4.1 Influencing the quality of end-of-life care in care homes

Much of the research examining end-of-life care for older people in care homes/long-term care facilities has consisted of descriptive studies (Oliver et al. 2004). However, in addition to ongoing work of Sidell et al. (1997) in compiling an in-house training manual for care home staff (Macmillan Cancer Relief 2004; Katz & Peace 2002), there have been two studies from within the UK (Avis et al. 1999; Froggatt et al. 2000), and one study from Pennsylvania, USA (Strumpf et al. 2004) in which the aim of the research was to bring about a change and improve the quality of care given to dying residents and their families. The two UK studies were undertaken prior to the commencement of this project.

The three-year study by Avis et al. (1999) involved the nurse managers of 43 nursing homes registered for 'palliative care', out of the 100 nursing homes within the

Nottingham Health Authority. A community clinical nurse specialist (CNS - palliative care) contacted each of the 43 nursing homes to offer three referral systems: a referral system for palliative care advice for residents; a referral system to request palliative care education for staff within the nursing home; and a referral system for support of staff. During the period of the research, 231 residents were referred and visits were made by the CNS alongside six 'peer support' district nurses. Education was given to 39 out of the 43 nursing homes. Most of the education involved a half-day session on grief and the awareness of dying (attended by 890 staff across the nursing homes). Further individual sessions on syringe drivers, principles of palliative care, and pain and symptom control were held. Outcomes from the evaluation highlighted the following: improved communication between the nursing homes and the local hospice leading to decreased isolation of nursing homes; greater understanding of some of the difficulties facing nursing homes that wanted to improve the quality of their end-of-life care; and greater equity of provision to specialist palliative care for nursing home residents. Involving nursing home managers in research projects and maintaining commitment is not easy (Chenoweth & Kilstoff 2002). One of the main achievements of the study by Avis et al. (1999) was the impact on such a large number of nursing homes in such a relatively short period of time. However, it would have been interesting to have had more information about the degree to which the six 'peer support' district nurses were able to sustain the influence of palliative care within the nursing homes following the end of the study.

Froggatt et al. (2000; Froggatt 2000a/b) undertook a 2-year palliative care educational project in which staff from 54 care homes (registered with RNHA) in England took part. Courses were designed for registered nurses, healthcare assistants and ancillary staff. The courses included a 12-day course for trained nurses, a 7-day course for healthcare assistants, and a 1-day course for ancillary staff. The educational project was unique in that it catered for *all* levels of staff including ancillary staff. The evaluation revealed significant individual learning. But when staff returned to their respective care homes, they found it difficult to effect change (Froggatt 2000a). It is unclear from the report to what extent nurse managers/owners of each care home were involved in the study, and whether if they had been more involved, this would have helped. The fact that education was given in a location outside the nursing homes might also have weakened the impact, especially if one considers the importance of team-building within care homes (Wicke et al. 2004)[17]. It could be argued that a more inclusive educational structure across all levels to encourage teamwork could have formed a stronger 'voice' to advocate good quality end-of-life care from within the care home. It might also have helped nurses realise the extent of healthcare assistants' experience in caring for residents who are dying, and at the same time help healthcare assistants realise the important role that nurses have in recognising dying in order to take responsibility for supporting the resident and family in the process of dying. Because of this, Froggatt et al. (2000) may have unwittingly re-enforced the hierarchical management style of many nursing homes. The educational project did encourage learning of individual participants, but on its own this was not able to influence organisational change. As they state, '*the importance of this issue ...*' [the issue that the education was unable to influence organisational change] '*...is a vital dimension to address for taking care practice forward*' (Froggatt et al. 2000: 12).

The third study (Strumpf et al. 2004; Tuch et al. 2003), published after the fieldwork of this present study had been completed, involved both practice and education, and was aimed at empowering staff within four nursing homes. Six nursing homes took part, four of the homes being intervention homes and two being 'control' homes with no intervention. The nurse specialist visited the four intervention homes regularly each week and picked up on the clinical issues as they were being reported and thus did not rely on staff to recognise dying. Key persons in each of the four intervention homes were appointed to take on the responsibility for co-ordinating the implementation of 'actions' designed by the researchers and the in-service palliative care training. Two out of these four homes also appointed specific healthcare professionals who formed a

---

[17] Wicke et al. (2004) highlight the difficulties of teamworking in the hierarchical management structures often found in nursing homes. They suggest there was conflict between the style of management in the nursing homes and the aspirations for teamworking.

'palliative care team' within the nursing home. Prior to the commencement of the study, the researchers, drawing from clinical experience and knowledge of the literature, identified three priorities to be addressed in the intervention nursing homes. These were: advance care planning; pain management; and psychosocial support of residents who were terminally ill. An audit tool was implemented to evaluate these specific outcomes following a resident's death. The nurse specialist spent 4-5 hours per week in each of the four homes providing formal and informal training of staff, and interacting with team members about relevant care planning. She was felt to be 'critical' in empowering staff to become proficient in improving palliative/end-of-life care. Success was greatest where there was greatest staff stability (in one out of the four intervention homes) and where discussion around palliative care needs of residents was integrated into the weekly care planning conference. Strumpf et al. (2004) report the challenges of team building amongst staff in the homes. Where there was a greater emphasis on individualised care of residents, it was easier for staff to understand the relevance of the palliative care approach.

Both the study by Avis et al. (1999) and that of Froggatt et al. (2000) lacked substantial 'insider' influence that might have helped to sustain improvement to end-of-life care. Both had also assumed that the contexts, which they hoped they were influencing, were ready and amenable to change. In the study by Strumpf et al. (2004), 'key' professionals within each of the intervention nursing homes were appointed, which clearly helped maintain momentum and interest in the study. Also, the clinical nurse specialist visited a number of times each week without waiting for referral. Again, however, the factors thought to be required to improve end-of-life care had been thought through by those undertaking the study with ideas coming from their own practice or from the literature (Strumpf et al. 2004). Staff within the nursing homes had not been invited to contribute their ideas as to what needed improvement.

Of these studies, it was that undertaken by Froggatt et al. (2000) that had considerable influence on confirming the methodological approach that this study should adopt. As a result of their research, Froggatt et al (2000) concluded that education on its own was not enough to bring about change. In order to bring about change one has to understand the context within which development of palliative and end-of-life care is to take place, with particular emphasis on the readiness for change. The importance of understanding the context prior to practice development initiatives where evidence of good practice is to be introduced has been highlighted (McCormack et al. 2001; Kitson et al. 1998). The similarities between practice development and action research have been reported (Ward & McCormack 2000; Garbett & McCormack 2002). This confirmed the appropriateness of an action research approach for this study in order to help develop high quality end-of-life care in nursing homes and to further the understanding of processes that block such a development in this setting. At the start of this study there was no reported research using action research to develop knowledge of end-of-life care in nursing homes.

2.5 CONCLUSION

This chapter has considered the appropriateness of a palliative approach to care for frail older people being cared for in nursing homes/aged care facilities. It has discussed the research, much of it descriptive, on the quality of end-of-life care currently being practised in these settings in the USA, Australia, Europe and the UK. It has highlighted three important studies (Sidell et al. 1997; Froggatt et al. 2000; Strumpf et al. 2003) that have been undertaken with the aim of actually influencing the quality of practice in nursing homes towards death and dying.

It was Froggatt's (2000a) evaluation of a palliative care educational study to systematically target nurses/care assistants/ancillary staff from 54 care homes (Froggatt et al. 2000) that became very influential in confirming the choice of methodology for this study. Froggatt (2000a) reported that although individual learning had been significant for staff undertaking the course, staff were unable to effect change back in the care home. This finding helped to focus attention on the importance of the nursing home context in relation to bringing about change in the quality of care given to frail older people at the end of their lives. An action research methodology that helps to understand the process involved in bringing about change was confirmed as a logical next step in the empirical research on end-of-life care in care homes. Action research was deemed a suitable research approach, not only because of its appropriateness for understanding the process involved in change, but also because of the possibility that this approach might be able to underpin a suitable way for the development of knowledge of end-of-life care specific to the nursing home context. The following chapter explains the action research approach taken in this study.

CHAPTER 3

ACTION RESEARCH AS A FORM OF SOCIAL INQUIRY

The last chapter gave an overview of the literature concerning the end-of-life care of older people. It highlighted difficulties of developing staff's knowledge of palliative care within nursing homes. As reported, an important evaluative study (Froggatt 2000a) of an education project to enhance palliative care knowledge for staff in care homes was instrumental in confirming the choice of methodology for this thesis, namely action research as a form of inquiry. The underpinning philosophy of action research is the emphasis on people within any one context coming together to transform a specific aspect of their work that they feel needs changing; it also concurrently examines the process of that change (Carr & Kemmis 1986).

This chapter highlights action research as a component of social inquiry. It includes a discussion of action research, and its position in the traditional paradigms of nursing research, with reference to some of the specific theoretical aspects of such a methodology. It offers an explanation of how I came to position my use of action research within critical social theory. Meyer (2000) stresses that the success of any action research should not necessarily be judged by the size of change resulting from it, but rather 'in relation to what has been learnt from the experience of undertaking the work' (p.180). In this study, the experience of learning was not just for those taking part in the study; the amount of knowledge and understanding that I gained through reflecting on end-of-life care in nursing homes as well as the theory of doing action research was considerable as will be seen as this thesis unfolds.

3.1 SOCIAL INQUIRY AND ACTION RESEARCH

Prior to the mid-1980s most nursing research was based within the positivist or hermeneutic paradigms. Quantitative and qualitative methodologies were often seen as 'opposed' to each other on opposite sides of the paradigm debate but often this distinction has been overstated (Webb 1989). With a more eclectic use of methods (Meyer 1993) and in particular the use of 'triangulation' as a method for increasing validity in research (Webb 1989), claims for the superiority of one paradigm over the other have decreased. Subsequently, this may have increased the acceptability of practice-based research such as action research.

Action research has only recently been recognised as a form of social inquiry (Winter & Munn-Giddings 2001). Although its history as an approach goes back over fifty years and some would say as far back as the late nineteenth/early twentieth century to the work of Dewey (Greenwood & Levin 1999), it is a more recent trend in researching nursing practice. There were a few advocates of action research in nursing as early as the late 1970s (Towell 1979; Sandow 1979; Lauri 1982). These pioneers emphasized the importance of continually reviewing, reporting back to participants, and modification of the process in order to bring about change. The change initiatives, however, were often presented from 'top-down' management positions. A strong 'problem-solving' approach was present that was not dissimilar to the nursing process being introduced as a way of organising nursing at the time these studies were undertaken (Waterman et al. 1995). In the early to mid-1990s, there was a greater focus on understanding the theoretical position of action research in nursing (Meyer 1993; Holter & Schwarz-Barcott 1993; Titchen & Binnie 1994; Hart & Bond 1996). This debate continues (Reason & Bradbury 2001), but there is greater flexibility for action researchers than in other methodologies to form research positions required to 'meet the specific conditions under which the research is to operate' (Gustavesen 2003, p.158).

3.1.1 History of action research

Action research first became popular as a research method in the USA during the 1940s/1950s. Kurt Lewin, (1890-1947) a psychologist whose research was based in social and experimental psychology, is the person linked with the founding of 'action research'. He constructed a theory concerning action research and made it a 'respectable' research approach for social scientists (McKernan 1991). Lewin defined action research as a spiral of steps, each involving planning, acting, observing and evaluating the process. These cycles involved the overlapping of action and reflection so that changes in plans were made as people learned from experience (Kemmis & McTaggart 1988). Lewin was particularly interested that inquiry should bring about a practical improvement rather than just the writing of books – '*research that produces nothing but books will not suffice*' (Lewin 1948: 203). However, a number of other people must take more credit for the development of action research than that reported in the literature (Gunz 1996). Jacob Moreno (1892-1974), a physician, social philosopher and poet who shared students with Lewin, reported the importance of integrating theory and practice by perceiving researchers as social investigators rather than just observers (Gunz 1996; Waterman et al. 2001). Collier, also working in the USA, was using the terminology of action research in his work on race relations as Commissioner of Indian Affairs (1933-1945). He was convinced that

> *'...since the findings of research must be carried into effect by the administrator and the layman, and must be criticized by them through their experience, the administrator and the layman must themselves participate creatively in the research impelled as it is from their own area of need'. (cited in Ebbutt 1985: 154)*

It is this emphasis on the layman's own area of need that was revolutionary as a way of research at a time when positivism was the dominant paradigm. The founding fathers of action research were interested in bringing about change in a democratic way. Some suggest that Lewin did not develop the theory of action research with respect to oppressive power bases in the context of poor manager-worker relationships (Waterman et al. 2001: 1). Nonetheless, his technique of field force analysis[18] (Lewin 1952) used to identify restraining and driving forces in relation to bringing about change highlights his awareness of the political forces within an organisation. It is likely that Lewin's untimely death at the age of 57 years prevented him from furthering his work around organisational power bases.

While action research was being developed in the USA, a group of researchers in the UK were interested in using action research to underpin the work of the Tavistock Institute of Human Relations (Holter & Schwartz-Barcott 1993). The group was interdisciplinary with a background in psychoanalysis and social psychology. This work has gradually evolved. It has been responsible for promoting an organisational type of action research (Emery & Trist 1965; Coghlan & Brannick 2001) that uses systems theory (Greenwood & Levin 1998) or a psycho-dynamic framework (Reason & Rowan 1981).

3.1.2 Definitions of action research

Names and definitions of action research are numerous[19]. Most reflect the philosophical stance of those action researchers who have created them. A comprehensive systematic review of action research in nursing by Waterman et al. (2001) defines action research by its inclusion of ten characteristics (see Box 3.1).

Two distinguishing features are fundamental to all approaches. These are the cyclic process involving some sort of change intervention and the partnership between researchers and practitioners (Waterman et al. 2001). Those within practice are encouraged to identify the difficulties that they want to research, and together with the

---

[18] Although rarely used in nursing, Lewin's (1952) field force analysis is a tool that helps to identify restraining and driving forces in relation to bringing about change. The emphasis is on reducing the restraining forces and is widely used in the change management of organisations determining whether change is viable and progress can occur.

[19] Names given to action research include:

action science, critical action research, participatory action research, co-operative inquiry, community action research, action inquiry, collaborative inquiry, educational action research, new paradigm research.

researcher come up with ideas to help overcome the problems. Greenwood (1994) has argued that the two main purposes of action research are to implement change and to generate theory. One could also argue that what needs to be made explicit about action research is the importance of critical self-reflection. Unless practitioners are encouraged to critically reflect on practice, it is unlikely that practice will change.

Box 3.1: Ten characteristics of action research (Waterman et al. 2001)

- AR describes, interprets and explains social situations
- AR incorporates a change intervention aimed at improvement
- AR is problem-focused and context-specific and future-orientated
- AR is a group activity – partnership between action researcher/s and participants
- AR is educative and empowering
- AR is dynamic, involving cycles of: problem identification, planning, action and evaluation
- AR uses reflection as a way of learning about situations and issues
- AR uses both qualitative and quantitative research methods to collect data
- AR acquires both practical and prepositional knowledge
- AR is able to validate old theories and/or generate new theories from practice

The involvement with others in the field and the emphasis on researching practice to bring about change makes action research more complex than its name might imply (Waterman et al. 2001). For the purpose of this study, the following definition of action research was taken:

> *'Action research is a form of collective self-reflective enquiry undertaken by participants in social situations in order to improve the rationality and justice of their own social or educational practices, as well as their understanding of these practices and the situations in which these practices are carried out.' (Kemmis & McTaggart, 1988: 5)*

The collaborative nature of action research is evident from the fact that it is not research 'on' people, nor is it research 'for' people, but research 'with' people (Reason & Bradbury 2001). Meyer (2000), in quoting from the seminal work by Carr & Kemmis (1986), simply suggests that action research incorporates three important characteristics: it is participatory; it is democratic; and it contributes to social change and social theory.

3.1.3 Philosophical perspectives and action research

There has been considerable debate in the literature (McKernan 1991; Holter & Schwartz-Barcott 1993; Meyer & Batehup 1997; Kemmis 2001) as to where action research is positioned within the philosophy of the social sciences. For a first-time researcher this can be very confusing and it was something that continued to interest me throughout the process of undertaking this research.

McKernan (1991) divides models of action research into the three classical philosophical paradigms: the scientific-technical view of problem-solving used by Lewin within his experimental group work of the early twentieth century; the practical-deliberative approach, where 'the action research develops a personal interpretive understanding from working on practical problems' (Elliott 1987: 157); and finally, the critical-emancipatory paradigm for educational action research that is argued by Carr & Kemmis (1985) and McNiff & Whitehead (2002) as being the only possible approach if those within practice are to be empowered to change.

Nursing researchers Holter & Schwartz-Barcott (1993) also name three action research approaches to each of the differing paradigms and label the different approaches as: the 'technical collaborative' approach, the 'mutual collaborative' approach, and the 'enhancement' approach. Unlike McKernan, they align these approaches with critical theorist Habermas (1972) and his theory of knowledge-constitutive interests. However, there is a lack of consistency in aligning these approaches with the work of Habermas, a critical theorist, but defining them across the three philosophical positions.

Meyer & Batehup (1997) agree with educational action researchers that the positivist and interpretist paradigms are inappropriate paradigms for action research. As Carr & Kemmis (1986) highlight:

> *'Both the interpretive approach and positivist approach convey a similar understanding of educational researchers and of the relationship to the research act. In both*

> *approaches, the researcher stands outside the researched situation adopting a disinterested stance in which any explicit concern with critically evaluating and changing the educational realities being analysed is rejected.' (p.99)*

However, unlike Carr & Kemmis (1986) and McNiff & Whitehead (2002), Meyer & Batehup (1997) are more cautious in placing all action research approaches within the critical theoretic paradigm. Greenwood (1994) also cautions using a critical approach to action research, suggesting that although there might be similarities between the professions of teaching and nursing, nursing does not boast such an autonomous position in practice as does classroom teaching. Nursing is bound up with colleagues from different disciplines and may therefore be exposed to more powerful health care professionals or managers when it comes to bringing about change. Even so, the emphasis on understanding power issues is a vital aspect of critical social science.

This caution around a critical approach to action research may have encouraged some nurse researchers (Meyer & Batehup 1997) to embrace action research as new paradigm research (Rowan & Reason 1981), which emphasizes the collaborative, psychodynamic nature of doing action research rather than using the language of critical social theory.

Nonetheless, Titchen (2000), in facilitating and developing patient-centred nursing as part of her PhD thesis, used a critical social science perspective. However, she also used phenomenological sociology and existential phenomenology to conduct her case study. Her integrated study design started with a phenomenological case study of 'skilled companionship' as a metaphor for patient-centred nursing. She later used this to help an expert practitioner facilitate ward nurses' development of this concept in nursing. She was able to model the role of 'critical companionship' through critical action research. This unusual approach by Titchen (2000), using more than one philosophical perspective, bridges the gap between opposing philosophical positions; using reflexivity is an important aspect of each of these approaches.

Amidst all the debate about which philosophical paradigm is most suitable for action research, Hart & Bond (1995; 1996) devised a typology specifically for health and social care, categorising different *types* of action research in order to clarify the complexity of different approaches. The four types[20] track the historical progression of action research as a strategy, from the experimental work of Lewin through to feminist approaches within social communities. Hart & Bond (1996) criticise Holter & Schwartz-Barcott's (1993) explanation of action research in nursing across the three philosophical paradigms as being 'static and rational rather than dynamic and non-rational' (Hart & Bond 1996:153). Hart & Bond (1995) state that different approaches of action research may be highlighted at differing stages in any one action research project; an approach of action research is thus capable of moving along the continuum from a consensus to a conflict model of society. The *experimental approach* would be positioned at the consensus end, with the *empowering* approach at the conflict end. Meyer (2000) has adapted the typology with a more in-depth look at the distinguishing criteria of each type. However, being eclectic and drawing on the different approaches of action research as suggested by Hart & Bond (1995) requires considerable knowledge and experience of action research. It also appeared to nullify the importance of a theoretical framework for the research. Waterman et al. (2001) attempted to use Hart & Bond's typology to categorise studies in a systematic review of action research but found it 'did not accurately reflect the findings in the included studies' (p.11).

For the reasons stated above, the use of the typology by Hart & Bond (1965) for this action research study was rejected. Once again I returned to the nursing literature to try and understand further the paradigm debate about action research with a particular

---

[20] The four 'types' or approaches to action research devised by Hart & Bond (1995) are:

(i) the 'experimental type' that arose out of Lewin's original scientific work in group dynamics.
(ii) the 'organizational type': it was Emery & Trist (1965), colleagues at the Tavistock Institute during the 60s and 70s, who recognised that the traditional way of organising work from the top down was hierarchical and not open to debate – a closed system – which participation in action research challenged.
(iii) the 'professionalizing type' that has been associated with education and healthcare.
(iv) the 'empowering type', working with social communities.

interest in critical social theory and the importance of being able to generate nursing theory (Holter & Schwartz-Barcott (1993).

3.1.4 Critical social theory and action research

Critical social theory can be best understood from the perspective of 'the empowerment of individuals in an attempt to confront the injustice of a particular society or sphere within the society' (Kinchloe & McLaren 1994: 140). It is concerned with bringing about improvement in the human condition. Kinchloe & McLaren define critical theory in broad terms that include:

> *'...all thought is fundamentally mediated by power relations that are social and historically constituted; ...facts can never be isolated from the domain of values; ...relationships between concept and object are never stable or fixed and often mediated by the social relations of capitalist production and consumption; ...certain groups in any society are privileged over others; ...oppression is most forcefully reproduced when subordinates accept their social status; ...language is central to the formation of subjectivity;...mainstream research practices are generally, although most unwittingly, implicated in the reproduction of systems of class, race, and gender oppression.' (Kinchloe & McLaren 1994: 139)*

The theory of critical social science emanates from what is known as the Frankfurt School (Held 1980). Social scientists within the Frankfurt school were concerned about the dominance of positivist science in providing knowledge about the world we live in. They were also concerned that '*philosophers have only interpreted the world, in various ways; the point is to change it*' (Marx 1845).

As one of the second generation critical theorists (Crotty 1998), Habermas (1972; 1987a; 1987b) believed that there were three ways in which knowledge was important to human beings if situations were to be changed:

> *'... three categories of possible knowledge: information that expands our power of technical control; interpretations that make possible the orientation of action within common traditions; and analyses that free consciousness from its dependence on hypostatized powers. These viewpoints originate in the interest structure of a species that is linked in its roots to definite means of social organization: work, language, and power.' (Habermas 1972: 313)*

What I believe Habermas (1972), from a critical social theorist standpoint, is saying in *Knowledge and Human Interest* is that change in society occurs by stressing the importance of critical self reflection and acting responsibly on that reflection in the interest of others (p.301-317).

> *'The methodological framework that determines the meaning of the validity of critical propositions of this category is established by the concept of self-reflection. The latter releases the subject from dependence on hypostatized powers. Self-reflection is determined by an emancipatory cognitive interest.' (Habermas 1972: 310)*

It is Habermas' (1972) use of self-reflection that emphasizes the ability of a human being to adapt to situations, balancing the instinctive nature concerning action along with what is considered to be for the good of a democratic society. For Habermas, the composition of knowledge about something *and* the human interest in it are categorised through the intermediary of work, language and power. It is the ability of human beings to critique what is going on around them (e.g. through self-reflection and dialogue) that overcomes the egoistic self-centredness of human beings. For Habermas, true self-reflection on the object and subject of knowledge in light of human interest meant that there was potential for the greater good within a society. Of course, this can sound utopian; there are of course people who not only feel but are disempowered.

For Carr & Kemmis (1986), and increasingly what was becoming my understanding of action research, Habermas's (1972) thesis of *Knowledge and Human Interest* is an important aspect of social inquiry. The positivist and interpretive research paradigms are not adequate in influencing society without the contribution of critical questioning.

> *'...For any reduction of the social sciences to the explication of subjective meanings fails to recognize that the subjective meanings that characterize social life are themselves conditioned by an objective context that limits both the scope of individuals' intentions and the possibility of their realization. By adopting an epistemology for the process of self-understanding that excludes critically questioning the content of such understanding, the interpretive approach cannot assess the extent to which any existing forms of communication may be systematically distorted by prevailing social, culture or political conditions' (Carr & Kemmis 1986, p.135).*

Carr & Kemmis (1986) and subsequently Kemmis (2001) highlight the importance of considering action research within a critical social science paradigm and within a Habermasian critique in particular. However, this still remains controversial.

Placing action research solely within a critical theory paradigm is severely criticised by Webb (1996)[21]. He is alarmed at the 'power' being generated by Carr & Kemmis (1986) in what he feels is a very biased and uncritical examination of critical theory and action research in education[22]. However, Carr & Kemmis (1986) do acknowledge the critics of Habermas' early work; they cite Bernstein (1976) and his particular criticism of Habermas' inconsistency in talking about theory and practice and yet ignoring the Aristotelian concept of 'praxis' in his early work; they also cite Gadamer (1975), who advocates that the interpretive paradigm is not as limited as Habermas appears to suggest in bringing about change in society. Fay (1987), in advocating the importance of enlightenment, empowerment and emancipation within critical social perspective, at the same time argues its 'utopian' qualities. There is no doubt that these arguments were to challenge my thoughts throughout this study, especially in light of the postmodern culture that now characterises western societies.

Despite these critics, there continues to be an increasing interest in a critical approach to action research from those within nurse education and healthcare management and practice (Titchen 2000; Bellman 1996, 1999; Holter & Schwartz-Barcott 1993; Manley 2000, 2001). Titchen (2000), Bellman (1999) and Manley (2001) all used a critical action research approach for their PhD theses. Bellman (1999) successfully developed patient self-medication, patient information leaflets, and patient-controlled analgesia in a surgical ward. In her thesis, she explores and exposes political dimensions of organisational culture, power and control. Manley (2001) used critical action research to

---

[21] Here I refer to Graham Webb (educationalist) and not the more familiar name in the nursing literature of Christine Webb.

[22] A special edition of Educational Action Research, 2005, 13 (3) brings together a number of critics marking the twenty years since *Becoming Critical: knowing through action research* was first published by Carr & Kemmis in 1983 and which led to the publication of *Becoming Critical: education, knowledge and action research* in 1986.

highlight the importance of the nurse consultant role in the transforming of nursing practice.

It is Kemmis (2001), however, who takes the discussion of critical social theory and action research further – a discussion of particular importance to this action research study. In mentioning Habermas's first thesis on *Knowledge and Human Interest* as a way of realising the importance of different kinds of knowledge and the importance of self-reflection in action research, Kemmis's critique highlights Habermas's (1984; 1987a) *Theory of Communicative Action.* It is the importance of dialogue and the task of an action research project to open up opportunity for people within the same organisation to communicate in order to achieve mutual understanding and the coming to a consensus about how things could be taken forward. During the study, I found Habermas's *Theory of Communicative Action* shaping my understanding and bringing greater meaning to undertaking this action research study and to the two actions that evolved inductively from the work in the nursing homes. As Kemmis highlights (2001), and as is explored further later in the thesis (see Chapter 8):

> *'The overall task of a critical social science, including critical action research is to explore and address the interconnections and tensions between system and lifeworld aspects of a setting as they are lived out in practice' (Kemmis 2001, p.98).*

Critical social science is concerned with addressing issues through dialogue in order to try to bring resolution of difficulties in what might be seen as a better outcome for all. Such a stance emphasizes the important dialectical relationship between the system of the place where practice is undertaken, and the lifeworld of those people as part of the system. There is also the tension between what we may or may not know in theory, and how we care in practice – a tension that can critically inform and improve both theory and practice.

3.2 WAYS OF KNOWING AND ACTION RESEARCH

One fundamental aspect of action research is the importance of gaining knowledge from practice (Holter & Schwartz-Barcott 1993; Titchen 2000; Meyer 2000). How we come to judge what credible knowledge is involves understanding what we mean by knowledge and whether practical knowledge is in fact 'scientific'. Those from a positivist paradigm would see knowledge '*as a free-standing unit, with an existence of its own, residing "out there" in books and databases. In this view knowledge is divorced from the people who create it*' (McNiff & Whitehead 2002: 18).

Action researchers do not regard there being only one way of knowing things. Instead, they understand the generation of knowledge to occur as a result of many ways of being in the world (McNiff & Whitehead 2002) and is rooted in the experience of 'doing' (Ladkin 2004). Nursing is a practice-based profession where nurses put into practice what they have learnt theoretically but also gain knowledge experientially (Benner 1984). Therefore there are different ways of knowing about reality. Action researchers in particular derive knowledge collaboratively with those involved in practice.

Ways of knowing have been theorised about in the nursing literature from as early as the late-1970s (Carper 1978). This knowledge can be categorised into scientific and experiential knowledge. Benner (1984) made the useful distinction in scientific knowledge between theoretical knowing ('knowing that') and practical knowing ('knowing how'). However, she also highlighted the importance of experiential knowing in experienced practitioners: the tacit or commonsense knowledge that comes from experience. This way of learning can be traced back to the philosopher/teacher John Dewey, '*we learn by doing and realising what came of what we did*' (Dewey, 1938 – cited in Rolf et al. 2001: 2). One of the ways to 'get at' experiential or tacit knowledge is through actively reflecting on specific situations in order to understand and critically analyse them. Both trained nurses and I undertook to write reflective diaries about issues that challenged us; group reflection work was also undertaken with nurses and care assistants and is explained further in Chapter 4.

Rolfe et al. (2001) believe that experiential theoretical knowledge can emerge through this critical reflection to inform scientific theory from practice. In nursing homes, most of the care of older people is carried out by untrained (but not unskilled) care assistants – people who have had little technical or scientific training. I was eager that this action research study should embrace care assistants' practical knowing and tacit knowledge of end-of-life care for older people, as much as the technical and experiential knowledge of nurses and managers of the nursing homes as we planned change together.

My own theoretical and experiential knowledge about palliative care was significant, although I knew very little about nursing homes. Greenwood & Levin (1998) highlight the importance of the action researcher having some substantive appreciation of the particular issues being researched. However, I was keen not to impose any theory of dying onto a non-hospice context. Those working in nursing homes would bring important local knowledge of practice, the setting and its history. Nonetheless, my knowledge of specialist palliative care was a potential threat for those within the nursing homes. How I presented myself was very important, so that this potential power would not block innovation. However, as will be seen in this study, despite a theoretical knowledge of how I might be seen as a threat, and despite being aware of the importance of us all being able to reflect on end-of-life care and to learn from each other's understanding and knowledge, my knowledge would nonetheless prove to be a stumbling block for some.

3.2.1 Linking critical reflection and action in action research

Critical social theory can be seen as a reflexive methodology (Alvesson & Skoldberg 2000) within which critical reflection plays a key part in the interpretation of social situations. Critical reflection and its interpretation are about the:

> '... *unconscious processes, ideologies, power relations, and other expressions of dominance that entail the privileging of certain interests over others.' (Alvesson & Skoldberg 2000: 144)*

Reflection, as part of action research, is therefore an intensely political endeavour (Kemmis 1985). Within action research, reflection is not just a personal encounter. If, as a result of reflecting, something needs changing, then such a change must be communicated. How that communication occurs and the willingness with which it is listened to can make or break an action research study. Reflection therefore is not just the prerogative of the action researcher and a few interested people; reflection is for all of those collaborating to bring about change. Because of this, the importance of management and not just practitioners being part of this reflective process is fundamental in order for change to occur. As Kemmis states:

> *'We do not pause to reflect in a vacuum. We pause to reflect because some issue arises which demands that we stop and take stock or consider before we act.' (Kemmis 1985: 141)*

Reflecting on action has been a theory to aid understanding for some time (Schon 1987; Argyris & Schon 1974). Kemmis (1985) highlights problem-solving, practical deliberation and speculative thought as three different forms of reflection. Problem-solving he states is about 'efficacy and efficiency of a technical nature' (p.142), and refers to those everyday problems that require a relatively quick decisive answer. Practical deliberation has a less specific outcome than problem solving. Here there is the need for greater understanding of the whole situation, where there is discussion about the most prudent course of action for the greatest good, but one that is not necessarily based on efficacy and efficiency. And finally, speculative thought involves critically examining and re-examining thoughts on a specific situation or issue in order to learn from it. Such reflexivity is not straightforward; however, during the process of undertaking this study, reflexivity became a skill that gradually developed both in me and those staff involved in taking part in the study nursing homes.

Reflection as part of clinical practice as a way of transforming nursing (Johns & Freshwater 1998) is now quite commonly understood. However, I was unsure whether staff in nursing homes would be familiar with such a concept because of their isolation from innovative learning (Sidell et al. 1997). I was also concerned what staff would think about reflection if they had not come across it before. To some extent all practitioners reflect on their practice, but often this reflection is not used to challenge existing theory and practice (Rolfe et al. 2001). Many nurses find it difficult to articulate what they know by experience (Fealy 1999).

My own experience of reflecting on practice had been totally intuitive; it had started as a ward sister at St Christopher's Hospice, London, in the 1980s. The senior registrar and I had encouraged other members of the team (trained nurses and care assistants) to meet with us regularly to reflect on the care given, following the death of a patient on the ward, in order to improve our practice. Staff were encouraged to talk freely, not only about the care given but also about their own feelings concerning the person who had died. These meetings had no thought out structure other than to give staff a specific time to sit down together a few days after the death and examine what had been good about the care, and what care we should be improving on. At that time, back in the early 1980s, I was ignorant of theories behind the gaining of different kinds of knowledge (Habermas 1972, 1974; Carper 1978) or indeed reflective practice (Schon 1987; Johns 2000). The completely intuitive act of a colleague's and my interest to support staff on the ward was brought back consciously to my mind during this study, when, in the nursing homes the staff and I were considering how to take forward actions following the initial exploratory phase in the first nursing home (see Chapter 6).

Rolfe et al. (2001) argue for the importance of such reflection, not only to bring about critical understanding of a situation but also to bring about appropriate learning in order to change individual practice with the aim of influencing the culture of the practice setting. Critical reflection therefore is 'meta-thinking' (Kemmis 1985), where thinking about thinking takes place, and the relationship between thoughts and actions is worked out. Enabling staff within the nursing homes to reflect not only on their practice but also on the context (i.e. the nursing home context) within which that practice was being carried out would be important in this study. Helping them to clarify difficulties in end-of-life care through reflection would hopefully not only bring about change in the immediate situation but also add to the body of knowledge involved with caring for older people dying in nursing homes. What is inherently involved in the creative process of critical reflection and action research is something called 'praxis'. This is discussed in the next section.

3.2.2 Linking theory and practice in critical action research

Until the early 1990s, most nursing theory was gained empirically, away from day-to-day nursing practice. This development of nursing theory away from practice does not reflect the practical nature of nursing as a profession and has created what is called the theory/practice gap (Rolfe 1993). There has been increasing recognition that nursing knowledge should be developed not only alongside practice itself but also through reflection developed from practice to inform theory (Kim 1999; Rolfe et al. 2001). Bridging what is seen as the theory/practice gap is increasingly debated in the academic literature. Some believe that this theory/practice gap needs closing (Rolfe 1993; 1997) while others strongly believe that this perceived gap adds a creative tension which enables clinical practice to be focused and up-to-date (Rafferty et al. 1996). Whether it needs closing or not, it is only by being involved as researchers *with* practitioners that knowledge about practice can be theorised and developed dialectically alongside practitioners. Bringing together theory and practice through reflection is a main feature of 'praxis' in action research.

Praxis is not a new concept but one that has been explored in depth more recently in the nursing literature (Penney & Warelow 1999; Holmes & Warelow 2000). Its roots are found as far back as the writings of Aristotle in the third century BC. More recently, 'praxis' has been associated with critical theorists such as Habermas (1974) and Freire (1970).

> *'According to Habermas, the dialectical interaction of a knowing person involved in social praxis is the essential ingredient of critical theory.' (Connor 2004:58)*

Rolfe (1993) defines nursing praxis as:

> *'[the] bringing together of theory and practice involving a continual process of hypothesizing and testing out of new ideas and modifying practice according to the results' (p.176).*

Praxis is knowing *why* we do something. It is reflecting on why something happened, in order to bring to the surface an explanation of what occurred and what could have been done to bring about a better outcome, or what was done that created such a good outcome. It is not static like technical knowledge. Bringing together practice and theory through reflection helps to advance learning. Rolfe et al. (2001) believe that acquiring experiential theoretical knowledge through critical reflection can create informal theory – theory that is acquired from practice. Whereas traditional theory is applied *to* practice, 'informal theory' is constructed *from* practice (Rolfe 1997). Known as nursing praxis, it is involved with narrowing the theory/practice gap (Rolfe 1993; Rafferty et al. 1996). Holter & Schwartz-Barcott (1993) highlight that action research helps not only to bridge the gap between theory and practice but between 'theory, practice *and* research by giving nurses in practice direct access to participation in the defining of research problems and in collaboration in the development of interventions'[23] (p303).

Meyer & Batehup (1997) are concerned that the focus of action research in nursing concentrates too much on action and not enough on the research aspects of the study. A greater critical approach to the process of change, not only from practitioners but also from the researcher, is an important way of theorising about action research. Using critical reflection as an inherent part of this study during the action phase and not confining it to the evaluation phase only, helped to illuminate this. For example, the action researcher pays particular attention to helping collaborators question and critically reflect on the 'values' which underpin their practice when bringing about change (Nolan

---

[23] Italics is my emphasis

& Grant 1993). My understanding of this developed during the study as I reflected on the process of doing action research in light of the relevant literature. At the beginning of the study, the exploratory phase was similar to a needs assessment – where staff talked about what they found difficult and how they thought end-of-life care might be developed. There was little explicit challenge to the staff values that underpinned their care for a resident who was dying. However, the drawing out of basic values about the area undergoing change and the clarifying of values across staff groups became a more important emphasis as the study progressed (see Chapter 6).

3.3 UNCOVERING AN ALTERNATIVE THEORETICAL PERSPECTIVE

Though I understood, at a conceptual level, what I believed to be an appropriate theoretical framework for this action research study, namely using critical action research to develop staff knowledge about palliative care in nursing homes in order to improve the quality of care in the last days of life, in actual practice I found it was much more complex. At one point I struggled with the appropriateness of a critical framework in light of some of the complex organisational issues. The whole process of doing action research appeared very messy (Cook 1998; Ladkin 2005). Nonetheless, persevering with what I believed to be an appropriate stance *through* the study was extremely helpful – not only illuminating the eclectic nature of action research but also, in the end, showing the usefulness of Habermas (1978) for my study, and in particular his *Theory of Communicative Action* (1984; 1987a). This section discusses my dilemma.

3.3.1 Critical social theory versus systems theory in action research

Through critical reflection, the staff and I were challenging our perceptions of end-of-life care in order to develop knowledge about high quality end-of-life care for older people dying in nursing homes. I was beginning to understand better the nursing home context around end-of-life care, beginning therefore to challenge my own perception from a specialist palliative care viewpoint. Staff in the nursing homes were beginning to understand their own vital role in caring for dying residents. Issues about communication and drugs to control symptoms were being addressed, but there were aspects of the nursing home organisation that made bringing about change difficult, and doubts about the utopianism of critical theory (Fay 1987) crept in. Although I thought I knew that researching practice and bringing about change would be complex, I was to learn that action research is known to reveal a greater complexity than conventional social science research (Greenwood & Levin 1998). Action research is about working with people's problems and bringing about a change for the better. Addressing such problems:

> *'involve[s]competing values and complex interactions between different people who are acting on different understandings of their common situation and on the basis of different values about how the interactions should be conducted' (Carr & Kemmis 1986, p.180)*

Action research is not about isolating issues and problems but working *with* those problems in real life situations in which different values are held. It is about embracing multiple ways of understanding situations and people (Ladkin 2004: 538).

The complexity of the nursing home system and issues of power made me think I was adopting a wrong approach. I was aware of the importance of dialogue as a basic principle of critical social theory. But when dialogue didn't happen with management – often because people were too busy – I began to think I was missing something. It even made me wonder whether a different theoretical approach was more appropriate. Because of the complexity and dynamism of action research, I flirted with the idea of complexity theory (Munday et al. 2003)[24].

> *'From a complexity perspective, development and change is viewed as a natural and evolutionary process ... complexity acknowledges the inability to totally understand the whole through an understanding of the parts' (Phelps & Hase 2002: 511-513).*

Complexity theory has evolved from systems thinking. I started to re-consider this as a framework as my reflective diary highlights:

---

[24] Complexity theory is gaining increasing attention not only in the biomedical aspects of healthcare but also in healthcare organisation (Plsek & Greenhalgh 2001). More recently, complexity theory and action research is being discussed (Davis & Sumara 2005).

> *'... In a way it would seem that one needs the reflective/empowerment of critical theory alongside highlighting the importance of the organisation which I have found so interesting in Senge's work and what Greenwood & Levin (1998) and Coghlan & Brannick (2001) ascribe to in action research with 'systems thinking'... there is this idea that critical theory is utopian (Fay's work) – it challenges the importance of increasing individual knowledge and empowerment but does it actually change organisations? How can organisations be challenged more through critical action research?' (adapted from my reflective diary: 29.07.02)*

Greenwood & Levin (1998) believe that the significance of general systems theory to action research is through the attempt that action research makes to bring about increasingly open systems in organisations. I was particularly drawn to Checkland's (1999) version of applied systems thinking. Certainly the more recent approaches to systems thinking such as Checkland (1999) and Senge (1990) acknowledge the role people play within a system. However, this has not always been the case; one of the arguments that Habermas (1987a) has about systems theory is that it marginalises people as part of a sub-system (this is argued further in Chapter 8 – see Section 8.2). Others (Spaul 1995; Flood & Jackson 1991) suggest that 'systems thinking' has moved from its original position within the positivist paradigm through the interpretive to the critical paradigm. Such a move has made systems theory more open to the importance of acknowledging people within the system and therefore a suitable framework in action research.

The other important aspect of systems thinking is about highlighting points of leverage (Senge 1990): finding the sticking points in the system.

> *'... the leverage in most real-life systems, such as most organizations, is not obvious to most of the actors in those systems.' (Senge 1990, p.114)*

Sticking points were indeed hard for the nursing home management to recognise. Staff were eager to speak to me about issues that they wanted to address. However, what seemed like good leverage points were being frustratingly obstructed by organisational issues to do with the nursing home context itself; some of which I was told, as an outsider, it was not part of my remit to address.

For me, using action research involved facing and learning how to deal with conflict (see Chapters 5 and 6) – not an uncommon feature in nursing homes (Forbes 2001). McNiff & Whitehead (2002) state that there is 'no overarching structure of values whereby conflict can be resolved. It is by engaging in dialogue that the assumptions held become understood and we accommodate each other better'. [p.3]. I began to understand that there were different theoretical angles that could frame action research, and to realise that the argument may be dependent on the position of those undertaking the action research and their individual experience, not only in the approach to action research but their status within/without the organisation. I once again returned to Habermas but this time to his thesis on his *Theory of Communicative Action* (1984, 1987a).

3.3.2 Rediscovering the importance of critical social theory

I had been struck by re-reading Kemmis (2001) and his deliberations about action research and its position in the theoretical debate and his insistence on discussing further the work of Habermas in relation to critical action research. His discussion not only includes Habermas's thesis on *Knowledge and Human Interest* but also Habermas's *Theory of Communicative Action* (1984; 1987a). As I re-read Habermas's *Theory of Communicative Action,* I became increasingly aware of the fundamental need for appropriate dialogue as the medium when bringing about change. In this theory Habermas (1984; 1987a) speaks about political systems and economy of the state and stresses the need for communicative rationality. The major conflict with modernity for Habermas is the increasing tension of the complexity of systems. Because of this complexity, Habermas believes that systems become self-sustaining and anonymous, increasingly pushing human elements out from the system. Within politics, the ultimate effect of this, for example, is that issues of public life are addressed through more and more legislation rather than suggesting that at least some of the issues might be better addressed through individual people taking responsibility, and through communication.

> *'Government can and must help where it can with better policing, tougher educational standards, welfare reform. But it's civil society that is the critical instrument of change.' (Sullivan 2005, p.2)*

The strongly hierarchical and in many ways political structure of the management system of nursing homes highlighted in this study might also be implicated. The voice of staff and indeed the voice of residents can be lost and these voices are not something that is easily heard within such a system. There was something holistic underpinning the philosophy of hospice care that was not part of nursing home management – at least in the management of the nursing homes in this study.

The more I read and understood the work of Kemmis (2001) and Habermas (1972, 1984, 1987a), the more I realised the importance of critical social theory and action research. I began to feel more confident about the position I was taking in framing this action research study.

3.4 MY POSITION AS AN ACTION RESEARCHER

All action researchers inevitably appear to draw from their individual work experience and how they view their world. For instance, Winter & Munn-Giddings (2001) propose that action research and critical realism are ideally linked to form a more pragmatic theoretical framework. Greenwood & Levin (1998), drawing from an anthropological and engineering background, highlight the relevance of systems theory and action research. McNiff & Whitehead (2002), from their background in education, draw on critical social theory and action research.

As someone interested in practice development and enabling nurses and care staff to gain new knowledge, it is argued here that critical social theory is an appropriate framework for this action research study: a study to enhance staff knowledge of end-of-life care in nursing homes and thereby to improve the care for dying residents and their families.

What is common to all these multiple perspectives in action research is the importance of valuing individuals and different standpoints; not assuming that one's own viewpoint is the correct or the best one but actively trying to find ways of accommodating multiple perspectives in order to change things for the better (McNiff & Whitehead 2002). Earlier in my work as a nurse specialist on a hospital-based palliative care team, I worked closely with a doctor whose underlying values stemmed from such a position. Unusually for a doctor, he always valued speaking with a care assistant or a ward clerk as highly as speaking with a professor in the hospital. The content of the discussion might be different but the respect with which he spoke to people and valued their opinion about something he needed to understand was no different. This experience helped to affirm my own personal viewpoint on valuing the contribution of other people in developing practice. In order to bring about change in the care of older people dying in nursing homes, it is important to hear the voice of those involved in caring, whether nurses or care assistants. They know the difficulties that they face and collectively are best placed in bringing about appropriate solutions. Nonetheless, there are also those who manage and own nursing homes. It is important to liaise with people at differing levels in the hope of bringing people to a greater awareness of individual responsibilities in achieving quality end-of-life care.

However, action research is more than respecting another person's perspective. It is also about changing things for the better and a personal commitment to such action (McNiff & Whitehead 2002). In many ways this involves risk; action researchers are unlikely to be those who are faint hearted or want a quick fix solution to problems.

3.4.1 'Insider' and 'outsider' roles in action research

There has been considerable debate in the action research literature about 'insider' or 'outsider' roles in the research process. The expression is likely to have come from organisational research or education research where people are involved in organisational change either from within the organisation (insider) (Coghlan & Brannick

2001) or invited in by the organisation to undertake a project (outsider) (Oja & Smulyan 1989).

In their research, Titchen & Binnie (1993a) used what they called a 'double act' within a collaborative relationship where one researcher was an 'outsider' to the organisation, and the other was a change agent/facilitator within the organisation – an 'insider'. Titchen & Binnie found this extremely useful. On the basis of evidence from various nursing studies, Titchen & Binnie (1993b) suggest that the 'insider' model is more successful. This is probably due to the greater integration of authority within practice that a nurse undertaking an action research in his/her own organisation is able to achieve; although the stress of continuing a clinical role alongside that of leading an action research study might be difficult (Coghlan & Casey 2001). Contrastingly, an outsider may be less blind to the context and therefore find it easier to see issues more clearly.

Meyer (1995) called herself an 'insider' during the commencement of her 'user involvement' study, having worked within the hospital where the study was taking place prior to going back as a full-time researcher. However, as a result of the arrival of a new manager on the ward where the study was being undertaken, Meyer felt like an 'outsider'. Being either an 'insider' or an 'outsider' is not exclusive. Titchen & Binnie (1993a) felt that the danger of burnout in the insider role was overcome by the supportive role played by Titchen as the outsider. Bellman (1999) describes being both an insider and an outsider within the same project because of taking the study to a different hospital from that in which she was working. Whatever stance is taken, the importance of reflexivity as an insider or an outsider is essential (Ruth 2002). Such critical self-awareness will help to question biases from either viewpoint.

I had been invited into the nursing homes as the owners/nurse managers volunteered to take part in the study. I was therefore an outsider. Greenwood & Levin (1998) describe the friendly outsider as a coach and not a director or a boss (p.106). They highlight the importance of self-confidence of the action researcher and a genuine interest in the project and those taking part. 'Being around' the nursing homes both during the exploratory phase and the action phase meant that from the viewpoint of staff, I was often accepted more as an insider. Like Bellman (1999), I was an outsider/insider. For those participating in the research at the level of the care of the residents I was very welcome. However, I was conscious that it was not so easy for the nursing home owners and nurse manager, who found my role threatening. Personal responses to situations and experiences were recorded in my field diary in order to bring greater understanding of this complex outsider/insider role.

3.4.2 Ethical issues as an action researcher

I have already hinted at some of the ethical issues of working with and participating in action research projects. The ethical parameters in action research are arguably less straightforward than that of positivistic science (Rowan 2001). In this section, I discuss these ethical issues from a theoretical standpoint; more general issues such as applying for ethical approval are dealt with in the next chapter, when I explain exactly how I went about this action research study.

i) Rigour

Reliability and validity have always been important ethical concepts by which people judge the credibility of research studies (Badger 2000). However, both reliability and validity are terms that resonate from a positivist paradigm (Hope & Waterman 2003). Reliability is particularly problematic in action research, as such a study cannot be replicated. Action research is concerned with the collaboration of practitioners in any one given practice situation; therefore reliably achieving the same results, as in repeating an experiment, is not going to occur. The different leadership styles and the different experience of nurses and care assistants in the two study nursing homes, despite many of the same issues in relation to caring for dying residents and their families, meant that staff chose very different actions to help improve the quality of end-of-life care. In action research, it is the in-depth description of the practice setting and the reported experience of those collaborating with the action research that will help readers judge for themselves the genuineness of a study (Titchen 1995).

Hope & Waterman (2003) highlight that validity in action research revolves around:

> *'the dialectical movement between action and reflection ..... As a consequence, needless vagueness and ambiguity is reduced, but amplification and deepening of the research focus is enhanced' (p.125).*

Such movement between action and reflection will also help to acknowledge individual bias (Titchen 1995). Trustworthiness is argued as being a more appropriate word than validity to describe the credibility of critical research (Kincheloe & McLaren 1994):

> *'[Trustworthiness] is helpful because it signifies a different set of assumptions about research purposes than does validity.'* (p.151)

Titchen (1995) describes the importance in action research of using one's beliefs and values consciously through a high level of self-awareness, while at the same time representing the experience and evaluation of those participating in the research. This is done through reflexivity and the keeping of fieldnotes as part of challenging oneself in light of differing opinions. An important part of this action research study is my attempt to use a critical perspective. Such a perspective recognises the important identification and subsequent exploration of tensions and contradictions within oneself and in the practice area (Waterman 1998). Using reflexivity to the fullest extent in exploring such issues can help demonstrate the transparency of an action research study and thereby heighten its trustworthiness.

ii) Power and Politics

Ladkin (2004) suggests that those researchers working with an action research approach need to be 'sensitive to issues of power, open to the plurality of meanings and interpretations and able to take into account the emotional, social, spiritual and political dimensions of those with whom they interact' (p.536). Imprecise as this may sound, what I believe Ladkin (2004) is advocating is the holistically ethical approach that those undertaking action research try to uphold. This expectation of Ladkin on how action researchers need to be prepared to react in complex situations while trying to improve practice, highlights some of the complexity involved in undertaking an action research study.

Judgements made by action researchers alongside those participating in the study are intensely political (Williamson & Prosser 2002) and action researchers have to be 'political entrepreneurs' in order to succeed (Coghlan & Casey 2001; Williamson & Prosser 2002). However, such 'judgement making' is often a juggling between one's own private critical reflection requiring considerable intuition and tact in knowing when and how to make such matters public, and, on the other hand, the more public activity involved in consulting and bringing illumination on important aspects that might help to bring about change. Change cannot be hurried and this 'to-ing' and 'fro-ing' between these two positions can be extremely taxing. Buchanan & Boddy (1992) describe such work as 'performing' and 'backstaging' which gives an interesting analogy to the drama involved in action research. There is a difference between these two positions; and, the public performing can be unnerving, especially when one is new to research and action research in particular.

iii) Professional morality

Because of the political nature of action research, action researchers need to be aware of doing no harm. Both Williamson & Prosser (2002) and Winter & Munn-Giddings (2001) make this point an explicit issue for action researchers. Respecting individual dignity, cultural diversity, and one's duty to care are important principles that underpin nursing but Winter & Munn-Giddings (2001) highlight these as issues specific in the more general practice of action research. Although a considerable amount of drive is necessary in undertaking an action research study, this drive must be bridled to avoid doing harm. Firsthand experience of this is a salutary lesson and is explored further in Chapter 5. A moral way to act in an action research study may be *not* to undertake any change if the situation is not conducive to that change. This underlines what both Meyer

(2000) and Waterman (1998) state in that the success of any action research project is not about the size of the change but to the attempt to bring improvement in people's lives. The degree of change therefore in an action research study *'is not a measure of its validity'* (Waterman 1998: 103).

iv) Collaboration and informed consent

Action research is unashamedly collaborative. Any perceived power that a researcher may have over practitioners is hopefully weakened by the keenness to highlight the expertise of practitioners in researching their own practice. Winter & Munn-Giddings (2001) emphasize the importance of all stakeholders being treated as co-researchers in relation to defining issues, collecting and analysing data and drawing conclusions. The difficulty of ascertaining who all the stakeholders are in the hierarchical structure of nursing home managements and having them draw conclusions in a setting where issues to do with recruitment and retention severely disrupt the day to day care can be difficult, but nonetheless important, in the validation of action research in nursing homes. Often, in action research, the full implications of collaborating on a project are not known. Although people may 'sign up' to participating in an action research study, it is very difficult to know in advance exactly what action will be undertaken, because of the inductive nature of the exercise. Issues of informed consent then are difficult[25].

In this study, it was important that not only practitioners but also nursing home managers/matrons be fully committed to the research in order for any successful change/development of practice to take place. The volunteering nature of those taking part in action research helps to establish this commitment, but there is evidence that commitment and 'signed up' collaboration at the beginning of an action research study can wane, once the journey has begun (Webb et al. 1998; Chenoweth & Kilstoff 2001). Chenoweth & Kilstoff (2001) found that although initial enthusiasm for the action research was considerable, as the study gained momentum the managers of the aged care

---

[25] Informed consent and its relation to this study are discussed in the next chapter (Chapter 4).

organisations taking part lost interest. A subsequent effect was the conflict amongst those staff who still wanted to work towards bringing about change.

3.5 CONCLUSION

This chapter has considered action research as an important research approach in social inquiry when the premise of the research is gaining knowledge from practice and understanding the practice setting better as a result of trying to bring about change. Action research is unique in its principle of informing theory from practice and thus bridging the theory/practice gap (Rolfe et al. 2001). This is achieved with the important focus on collaboration and the encouraging of practitioners to research their own practice through critical reflection.

Action research has been a form of social inquiry for decades but has only been recognised as a legitimate research approach for nursing in the last fifteen years. The differing theoretical perspectives of action research and the subsequent difficulty of finding a match in order to frame this study have been discussed. A critical theoretic paradigm was chosen because the underlying purpose of this study is to empower staff through improving their knowledge of high quality end-of-life care for older people dying in nursing homes.

Finally, the chapter has considered some of the ethical implications that are specific to action research: the importance of collaboration and recognising bias; issues of power; and being sensitive to differing viewpoints while at the same time being inclusive to those stakeholders committed to taking part. Through this chapter I have tried to show that:

> *'..[critical] action research aims towards helping practitioners to develop a critical and self-critical understanding of their situation ... It aims to connect the personal and the political in collaborative research and action aimed at transforming situations ...' (Kemmis 2001:92)*

CHAPTER 4

HOW THE STUDY WAS CONDUCTED

This chapter describes how I undertook this action research study in collaboration with staff and managers from two independent nursing homes. Following the main aim and objectives of the study, an outline of the study design is given which also provides an overview of the two major 'actions' instigated in the nursing homes. In Section 4.3, I describe how nursing homes were accessed and how nursing home managers volunteered to participate in the study alongside the final selection process and timing of the study. I give a detailed account of the data collection methods and analysis is described in Section 4.4 and Section 4.5. Finally, I discuss some further ethical issues in relation to informed consent and confidentiality.

4.1 RESEARCH AIM AND OBJECTIVES

The aim of this study was to develop knowledge and practice in relation to end-of-life care in two independent nursing homes through a critical action research strategy. My original questions that framed the study and were presented to the ethics committee for approval before going into the field were:

i) How are dying residents/families cared for in the nursing home?
ii) What problems do staff experience in their care of dying residents?
iii) What factors impede high quality care of dying residents in nursing homes?
iv) Who is involved with caring for dying residents and how do their roles interlink with each other?

v) What aspects of specialist palliative care education are appropriate?

vi) How best can 'the palliative care approach' be integrated in nursing homes?

vii) What can be learned from the process of attempting to bring about a change to the quality of palliative care for older people in nursing homes?

Ethical approval for the study was granted. After commencing fieldwork and with my understanding of the theory of action research deepening, the research questions became more focused into the following objectives:

- To identify problems that staff experience in caring for a resident who is dying and how these problems impact on the provision of high quality end-of-life care for older people in nursing homes
- To examine the roles of nursing homes, and of staff in relation to the end-of-life care of older people
- To examine with staff what actions could successfully be implemented in order to promote high quality end-of-life care, and to evaluate the impact of these actions
- To describe what can be learned from the process of using action research in order to develop knowledge and practice in relation to the end-of-life care needs of older people in nursing homes

4.2 DESIGN

Action research requires a flexible design since the whole process is driven collaboratively with those in the setting where the research is being carried out. Nonetheless I felt it important to have a broad outline to frame the study at the outset. The outline consisted of three phases in each of the nursing homes:

- The exploratory phase – phase 1
- The planning and facilitating action phase – phase 2
- The summative evaluation phase – phase 3

4.2.1 The exploratory phase – phase 1

The exploratory phase was an intense period of involvement in the nursing home. It lasted between 2-4 months in the different nursing homes. During this 'pre-innovation phase' (Meyer 1993), I spent two/three shifts a week during the first month of this period, working early shifts, late shifts and night shifts in order for me to get to know staff and the residents, and for them to get to know me. I worked alongside the caring team, specifically attaching myself to those caring for residents who were thought to be more poorly and therefore potentially dying.

During this period, I made a formal presentation of the study, emphasising the importance of its collaborative aspect. Because I had got to know staff as I worked alongside them, the majority were inquisitive enough to come along to the presentation. I was surprised at the amount of trust that had already been built up during the first four weeks of this exploratory phase. Open discussion about collecting data during the exploratory phase revealed that most staff were keen to participate and to be involved. Many were very interested to see how their care for dying residents might be developed and how knowledge might be gained, following the initial presentations. Staff who were keen to be involved in the study were given an information sheet (see Appendix 1).

The key focus of the exploratory phase was an evaluation of what staff felt about their current practice in caring for residents who died in the nursing home and the difficulties they were facing (the data collection methods used for this are described in Section 4.3). A critical ethnographic style of evaluation was used that values the history of the setting in which the research is being undertaken and allows the researcher to consider social and organisational practices (Manias & Street 2001). Such an approach also provides an opportunity whereby staff can express their ideas both collectively and individually, and work collaboratively to transform their clinical practices (Street 1995). Prior to going into the nursing homes, the focus had concentrated more broadly on the concept of the 'palliative care approach' (see Section 2.1). One of the research questions had been about how best to integrate the palliative care approach – an holistic concept that is inclusive of the care of the person with incurable, life-threatening illness and their family; the approach attends to physical, psychosocial and spiritual issues. However, during the exploratory phase the emphasis began to change, as staff appeared to want to focus on death and dying rather than the broader application of palliative care. I was conscious that there was little understanding about the concept of palliative care, especially in NH1. The reason for this, in particular the emphasis on functional rehabilitation in nursing homes, would become clear as I continued to be involved in the study. However, at this point, creating a focus for improving knowledge and practice in relation to residents who were dying was more appropriate starting place. I hoped that as together we critically examined attitudes and practices about death and dying, I might help to highlight other issues to do with palliative care more generally, that staff might want to address at a later date.

4.2.2 The planning/facilitation phase – phase 2

An analysis of data collected during the exploratory phase was then made and presented as an interim report to the nurse managers/owners/management of the two main nursing homes. The writing of the interim report was an important step marking the beginning of the facilitation phase. It enabled me to formally analyse material that had been discussed and collected during the exploratory phase and validate its findings with staff in the nursing homes. This material forms the basis of one of the analysis chapters (Chapter 5).

The reports were written and given to colleagues from the steering group to read, prior to their being given to the nurse managers/owners/management of the nursing homes (NH1 and NH2a). However, in NH1 the owners were unhappy about a number of issues. They wanted me to omit comments about the organisation of care. For them, comments about their models of care, for example, were irrelevant to developing care about death and dying. After a lengthy discussion that highlighted the importance of the context when developing practice, most of the original text remained and the report was then circulated to staff. The situation opened up a dialogue about aspects of the organisation that on reflection was very useful, especially as the way things were done had never previously been seen to be 'challenged'. It is interesting to note that Holter (1998), in her PhD using critical action research, suggests that reporting back the results informally may be less threatening.

Once the formal report had been read by nurse managers/owners/management, arrangements were made to report back verbally to staff in the nursing home. Group meetings were arranged and attended by a large proportion of the staff. The informal feed back session consisted of a group discussion open to all staff and managers, where ideas were sought as to how to take the project forward in the individual nursing home. The reporting back clarified topics highlighted by the care assistants and nurses, and confirmed the themes that had arisen out of the data collection. Solutions to the problems were then collaboratively discussed, both during the feedback sessions, and as an informal on-going collaborative act with staff interested in the study.

As a result of the discussions people began to suggest how they wanted to see things changed. Smaller or minor actions alongside more overarching or major actions were being developed as a result of the feedback. The more minor[26] actions involved the everyday practice of palliative care: for example, helping residents look more comfortable with pillow positioning; organising a written procedure for last offices; teaching sessions on setting-up of a syringe driver; arranging staff exchanges between the nursing home and the Hospice; offering tutorials on communication/symptom control; developing a pain assessment chart, etc. Such issues were generally covered with the specific individuals concerned as I targeted my working alongside, or were clarified with nurse manager/s later by way of tutorials and were spin-off cycles of action (McNiff & Whitehouse 2002) as the practice setting required.

> *'I like the notion of a systematic process of observe, describe, plan, act, reflect, evaluate, modify, but I do not see the process as sequential or necessarily rational...The visual*

---

[26] Minor action cycle is not seen as less important but represented as a response/action to a more individual need

> *metaphor I have developed is an iterative spiral of spirals, an exponential developmental process.' (McNiff & Whitehouse 2002, p.56)*

The two major[27] actions are listed below as Action Cycle 1 and Action Cycle 2 (see Chapters 6 & 7). These became overarching cycles of the more minor action cycles that were being undertaken.

ACTION CYCLE 1: Creating a culture of learning through the development of 'Collaborative Learning Groups' (CLGs) following a death in the nursing home

One of the main themes arising out of the exploratory phase, and reported further in Chapter 4, was that concerning the lack of a learning culture within the organisation of nursing home care. Staff were eager for more knowledge: that was why they wanted to participate in the action research. However, encouraging a learning culture as a part of practice was a new concept. Staff talked enthusiastically about the different subjects for tutorials that could be held. I voiced my concern as to how many staff would regularly come in or stay for a tutorial. I was also conscious that for many care assistants, learning through tutorials could be very dry. We spoke about using reflection as a way of learning – reflecting on the care of residents whom they knew or had known. To some of the senior nurses, this was a whole different way of gaining knowledge and they were apprehensive. However, one of the owners of NH1 was eager for staff to try it out.

The 'collaborative learning groups' therefore became a major action (in NH1 & NH2a) under which the detail of caring for a resident who was dying or had died in the nursing home could be discussed as a team. In total, 22 collaborative learning groups were held; ten of these were tape-recorded and provide data on significant learning that occurred as a result of the groups (see Chapter 6).

---

[27] Major action cycle represented an overarching 'action' specific to an individual nursing home and is what is reported in this thesis

ACTION CYCLE 2: Anticipating dying – the development of an 'Integrated Care Pathways for the Last Days of Life'

The second major action (see Chapter 7) occurred as a result of an interim evaluation questionnaire sent to staff at NH2a when the nurse manager handed in her notice to leave. Because this nurse manager had been so supportive of the project, staff had grown in confidence about how they wanted to improve their care for residents dying in the home. One of the trained nurses, in remarking about the collaborative learning groups, mentioned the importance of having a tool to guide the action *before* a resident died. She had valued the groups but with the instability of staff and the fact that she worked part-time, this particular nurse felt that a tool to guide care in the last few days of life would be important. An integrated care pathway for the last days of life (ICP) became a tool that staff were involved in adapting and then implementing in NH2b to assist in giving more attention to the process of dying.

4.2.3 The summative evaluation phase – phase 3

The commencement of this final evaluation phase was influenced by different events within the different nursing homes. Being true to action research meant that the evaluation of small spin-off cycles was going on throughout the time in the nursing homes: e.g. interviewing staff about what they had learnt by spending time at the Hospice; and evaluating each collaborative learning group by getting members to ask each other what we had learned. This added to the accumulative data that was being fed back during the process of doing the research. My analysis therefore of this action research was on-going. However, there came a time when I needed to leave one nursing home to start in another, and then finally to leave the nursing homes altogether. At this point, a more formal summative evaluation was undertaken and I used an eclectic range of methods to suit the situation in each nursing home (see Box 4.1).

Action research could be seen as an on-going cycle of planning action, evaluating that action and implementing further action in order to improve practice and bring about change. However, in this study there was an ending point in each of the nursing homes.

Although the idea of one year in a nursing home had been suggested to managers of nursing homes as an appropriate period at the initial presentation at the Hospice, it had not been formally discussed with management in the nursing homes that then took part (NH1, NH2a & NH2b). In many respects, I found it very difficult to know when to leave a nursing home, especially with the depth of friendship and collaboration that had been built up between the staff working with residents and myself.

Box 4.1: Summative evaluative methods used in the nursing homes

Both qualitative and quantitative data collection methods used, including:

- NH1: a final group interview, interview with owner, and an evaluative questionnaire (see Appendix 8)
- NH2a: Evaluative questionnaire
- NH2b: Interviews (including telephone interview) with 'core group' involved with adapting and implementing ICP document; interview with a relative; questionnaire to remaining staff

In NH1, the evaluation phase appeared to be precipitated by a time factor and the desire not to overstay any welcome. I had been involved in the nursing home for 10 months; and although the staff really appreciated what we had done together, this period had not been altogether easy for the management. In their minds they had only planned for me to stay the year and since most of the original staff on the project had left, it felt appropriate to leave. In NH2a, the summative evaluation was precipitated by an event within the nursing home management that resulted in the nurse manager's handing in her notice. As a result of this, staff began to leave and I was conscious of losing important evaluative data if I didn't act quickly. The idea for one of the main actions for this study evolved out of this evaluation and involved my staying on and working with the new nurse manager (NH2b). I left NH2b following the pilot of the ICP documentation.

After three years in the nursing homes (NH1, NH2a & NH2b), and with the nurse manager of NH2b also handing in her notice, it felt a natural time for me to leave the field. However, a further cycle of practice development was initiated as part of the Hospice project (see section 8.4.3), thus highlighting the inevitable on-going cycle of action research (Winter & Munn-Giddings 2001).

4.3 ACCESS AND PARTICIPATION

Nursing home managers from nursing homes within the city, who had returned questionnaires from the health authority-wide survey on death and dying in nursing homes (see Chapter 1), were sent a further letter inviting them to volunteer to take part in the next phase of the project, which represents this action research study. The nurse managers/owners of 14 nursing homes responded and attended one of two meetings held at the Hospice[28] to find out more about the study.

4.3.1 Volunteering to take part

In order for successful change to occur in an organisation, it is important as a first step for the management of that organisation to want to change. Emphasis therefore in the selection process of action research studies is put on organisations *volunteering* to take part (Pontin 1996). It was hoped that if nurse managers/owners volunteered, then they would be more willing to critically examine their practice. Pontin (1996) in his action research not only had staff on wards volunteering to take part, but the ward staff had to make a competitive case for being involved. At the time, I did not feel it appropriate to force competition on nursing home staff to take part. In light of the isolation of nursing homes from teaching/practice development (Sidell et al. 1997) I was concerned that such competition might put them off. I felt that a response to the substantial survey questionnaire as well as attendance at the meeting about the action research study were already proof of considerable interest in wanting to develop their practice.

---

[28] As the Hospice was funding the project, I had an office there plus access to seminar rooms.

4.3.2 Nursing homes selected to take part

Each nurse manager/owner who attended one of the presentations about the study was given an information sheet concerning the project (see Appendix 1). Considerable explanation was given about the intensity of involvement in action research and that only two or three nursing homes could be selected[29]. Out of the fourteen nursing homes represented, as many as twelve nurse managers/owners wanted to be involved, which made some sort of selection necessary.

Selecting the nursing homes was not straightforward. There was a wide variation between the nursing homes being volunteered. Most nursing homes were of medium/large size having between 40 - 80 beds, with the majority being part of a large corporate nursing home organisation; there were three nursing homes that were small and privately owned. One organisation was specifically 'non-profit' making. A sub-group of the steering committee at the Hospice was involved in the discussion and although initial discussions were about the type and size of nursing home, the final selection was more about who was realistically *able* to take part. Many of the nursing homes that had volunteered were excluded from the study due to a variety of reasons (see Box 4.2).

A decision was made to start in one of the nursing homes (NH1) that was small and privately-owned (25 beds), and to allow the further selection to be influenced by the experience in NH1. Following nine months in NH1, contact was made with a 36-bedded independent privately owned nursing home, the majority of whose residents had been discharged from NHS long-stay, psycho-geriatric wards. However, after a 2-month exploratory phase in this nursing home I realised that there was a considerable problem with recruiting trained nurses and that all the nurses for the next few months were coming from an agency. When the nurse manager hinted she too might be leaving, I was

---

[29] At this point in the overall Hospice project, I was under pressure to consider more than one nursing home as a single case study.

aware that there would be no 'insider' to help sustain the action research after I left. I therefore withdrew.

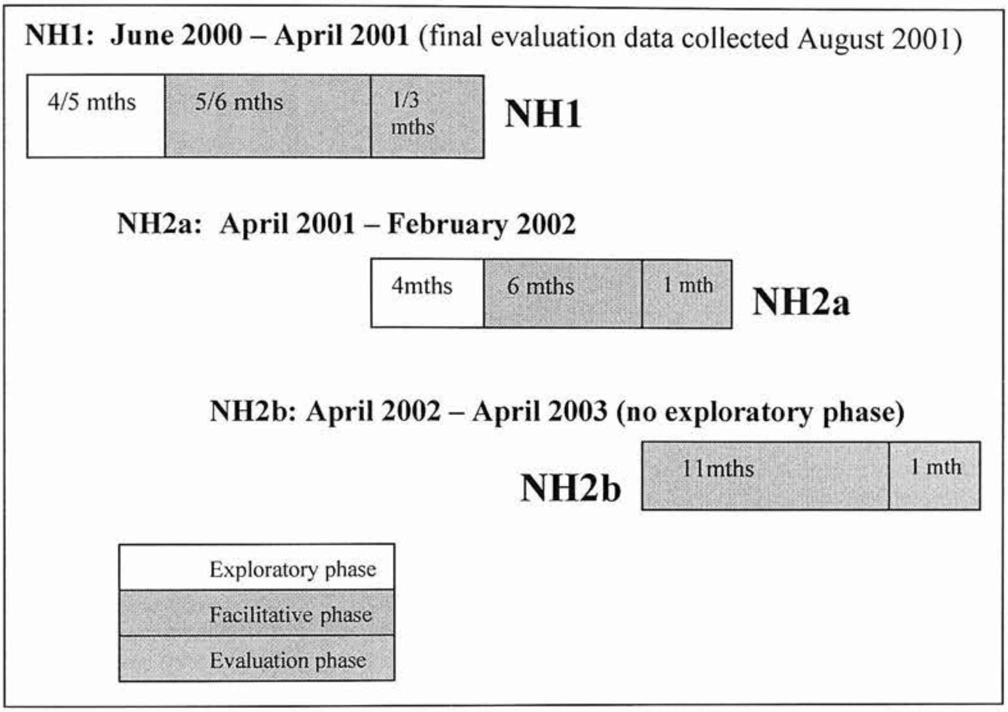
Box 4.2: Reasons that prevented interested nursing homes from taking part

- a nursing home that suffered a natural disaster (flood) causing all residents to be relocated for a year to other nursing homes
- a dual-registered home that had a large proportion of learning disability residents with a low death rate
- a nursing home whose nurse manager was on the steering group of the project
- a nursing home that had financial problems on two occasions near the beginning of the study and was therefore thought to be too unstable
- a nursing home that was part of a large corporately-funded organisation whose management group would not allow their involvement
- a nursing home whose deputy manager (the person interested in the study) was to be taking a year out
- a nursing home whose management board would not financially support any education
- a nursing home whose nurse manager had only been in post one month

I returned to consider the original list of nursing homes eager to be involved. One nursing home had not been initially selected because the nurse manager, at that time, had only been in post one month. However, following my time in NH1 and an interest to work with a non-profit making nursing home organisation in contrast to the 'for profit' emphasis of NH1, I decided to approach this 42-bedded nursing home (NH2a).

Again after only 9 months of working with the staff in NH2a, the nurse manager unfortunately handed in her notice. She was being asked to make cuts that she did not agree with and did not feel listened to. A decision to stay on at this nursing home and call it NH2b was made for a number of reasons. Firstly, the whole nursing home world was beginning to feel very unstable with press reports of nursing homes closing due to financial problems and difficulties in recruiting staff. I was very aware that the same thing could happen in yet another nursing home. Secondly, I wanted to know what it was like to ride out the inevitable period of instability while a new nurse manager settled in. As it happened, the new nurse manager of NH2b was keen for the project to continue. The actual time spent within the nursing homes was three years and this fell roughly into three one-year periods (see Box 4.3).

Box 4.3: Time span of project



All the nursing homes had different styles of management, so in many ways it felt like I was working in three different nursing homes. Working in the different nursing homes became an action cycle in itself as *I* went through the process of learning about action research, particularly in relation to encouraging greater collaboration.

4.4 DATA COLLECTION METHODS

Data were collected using the following methods: focus groups, observation and the keeping of fieldnotes, in-depth interviews and the collecting of documentary evidence.

4.4.1 Focus groups

Most of the literature written around group interviewing is taken from the focus group literature. Kitzinger (1994) defines focus groups as:

> *'... group discussions organised to explore a specific set of issues...the group is 'focused' in the sense that it involves some kind of collective activity' (p.130)*

It was this 'collective activity' that was important to capture. Macleod Clark et al. (1996) used focus groups as part of their study with student nurses while others (Reed & Payton 1997; Lane et al. 2001) used them to ascertain the views of informal care assistants, and the views of older people moving into care homes. Focus groups have also been seen as an important catalyst for participatory inquiry research (Lane et al. 2001) and for exploring cultural values (Robinson 1999) - two important factors for this critical action research study.

It was important to be able to hear the voices of those who were actually caring for older people dying in nursing homes and in particular, care assistants (and ancillary staff) alongside the nurses. I was conscious that care assistants could easily feel awkward in a one-to-one in-depth interview or in filling out a lengthy questionnaire. In fact it has been reported that care assistants find completing questionnaires difficult (Redfern et al. 2002). I had observed care assistants sitting and chatting together over coffee and had heard them give their opinions on issues. I was keen to capitalise on this oral tradition. It seemed a natural way to explore their skill. I was also mindful of wanting to demonstrate the importance of participation at the beginning of the study and to promote the idea that we were researching together. All too often in the hierarchical structure of nursing homes, care assistants feel their voice is not heard (Banaszak-Holl et al. 1996). Having care assistants taking part in the focus group alongside nurses would hopefully emphasize the important role care assistants play, not only in supporting the resident and family but also the nurse. Nurses too would understand more fully the significant role of the care assistant who despite not having undertaken training was not unskilled. At this point in the study, in order that care staff and nurses felt they could speak unhindered, the matrons/managers agreed not to take part in the focus groups.

A notice was put up detailing information about the focus groups once the presentation of the research had been given. In NH1 the groups were convened prior to the 'late' shift and accompanied by a snack lunch. In NH2a the time chosen by the nurse manager was following the afternoon hand-over. On all occasions, those who came to a focus group were paid by the nursing home for their time. In NH1, the focus groups were strictly regulated to one hour in order that it did not interfere too much with the daily routine of the nursing home. The time issue was more relaxed in NH2a and since they were held following the afternoon hand-over, these groups did sometimes extend over the hour allocated. A total of five focus groups for staff and one focus group for residents were conducted [two in NH1 and four in NH2a]. The discussions were full of 'stories' of residents whom the staff had cared for previously and who were remembered because of a particularly 'good' or 'bad' death.

There is perhaps a tension in using the word focus groups within a critical action research paradigm (McNiff & Whitehead 2002). However, for me, it gave an important structure within which to do a group interview.

i) Conducting the focus groups

Prior to the focus group in the nursing home commencing, time was given to explain the study and in particular the purpose of the focus group in case people had not heard about the study or read the information about the research available on the staff notice board. Members of the group were then asked to sign a consent form (see Appendix 2a). Participants were assured they could leave the discussion at any point if they so wished. All focus groups were tape-recorded except for focus group 4 (NH2a) when the tape recorder failed; on this occasion written notes made to capture as much of the discussion as possible were compiled immediately after the focus group on my return to the Hospice.

The groups represented staff from both day duty and night duty, and all groups started with an icebreaker that I hoped would help relax the group. Participants in the group were encouraged to introduce themselves as well as say a little about their favourite time of day. This often caused spontaneous hilarity within the group. Because they all knew each other and some had worked for many years in the nursing home, the icebreaker came to be a tool that helped me feel more relaxed. Just to hear the laughter made me aware that although we would be discussing difficult issues and potentially there would be sad stories told, the care assistants were often very supportive of each other when given an opportunity. During the groups many of those taking part wanted my opinion on certain aspects of death and dying. There was a huge temptation for me to join in the discussion and my expertise in palliative care felt like a disadvantage as I felt it difficult to be naïve in my questioning. I had to continually check myself to probe for what was important about end-of-life care in the nursing home setting.

For all but two of the six focus groups carried out in the exploratory phase, a specialist nurse from the Hospice community care team acted as observer and scribe to the group. This was extremely useful. Not only was it good to chat about the group with someone immediately afterwards, but having written information on what they had observed during the discussion added to the quality of interpretation in relation to the interaction within the group. It was useful to have a written observation of the group dynamics when re-listening to the tapes. Table 4.1 details the number of focus groups and those attending in each nursing home.

The focus of discussion (see Appendix 3) in all but the last group interview was to discover how staff felt about the care they gave to dying residents and what was important to them in the process of such care. The focus group undertaken with residents (FG 6) was held in NH2a following the death of a resident in the home when the nurse manager had felt strongly that there needed to be greater openness (see section 5.3.1). In order to reassure staff in their fear of talking about the death of a resident to other residents in the home, FG6 was set up with the aim of finding out how other residents wanted information about the death of a fellow resident communicated. Much of the data from this focus group[30] confirmed the importance of a greater openness around death and dying, but is not specifically drawn upon in this study.

Table 4.1: Staff participating in focus groups

Nursing Home	*FG*	*Length of Time*	*People present**	*Position of those attending*
NH1	1	45 mins	7 + 2	CAx3, Nx3, Dx1
NH1	2	50 mins	7 + 2	CAx5, Nx1, Dx1
NH2	3	60 mins	7 + 2	CAx6, Nx1
NH2a	4	55 mins	8 + 2	CAx7, Nx1
NH2a	5	75 mins	5 + 1	CAx2, Nx2
NH2a	6	65 mins	7 + 4	Residents of nursing home

On one occasion there was no moderator/helper present (FG 5)
D=domestic; CA=care assistant; N=nurse (F/T P/T)
* People present consisted of nurses/carers or residents (in the case of FG6) + those present who were facilitating the group

There was little need to have worried about how staff would participate in the focus groups. Using focus groups appeared a natural way to encourage staff in nursing homes to share and discuss together their different ideas and explanations of how older dying people were cared for. On two occasions, staff remarked that it was good to get the opportunity to sit down together and discuss a topic. In nursing homes, it is difficult to find a particularly soundproof room; either the noise of residents' buzzers or the awareness of activity going on in the home could be heard over the discussion. However, many of those participating appeared quite oblivious of any disturbance.

---

[30] FG6 was facilitated collaboratively by the nurse manager and myself, with a nurse and a carer present to give emotional support if necessary. All but one of the residents present felt very at ease talking about death and dying. Discussion highlighted the importance for residents to be told when another resident they had known had died and to be given the opportunity to visit them if appropriate. There was some discussion on 'living wills' and their desire to be in control. The staff involved in the group were particularly impressed by the experience. The residents did ask for a repeat session but when the nurse manager of NH2a handed in her notice, the emphasis of the study changed and a further FG was felt to be inappropriate.

A final focus groups was also held at the end of the study in each nursing home and added to the other data being collected to gain a summative evaluation. However, in all nursing homes, many of those who had participated at the beginning of the study had left when the final evaluation was being undertaken.

4.4.2 Observation and the keeping of fieldnotes

Observation is a key skill of a good nurse practitioner (Parahoo 1997) but as a nurse, I was still apprehensive when I first entered the field as a researcher to observe alongside participating with staff in their care of residents who were frail or dying. Entries from my personal diary portray the apprehension I felt:

> *'Very aware of feeling apprehensive about what I should be observing and recording in my fieldnotes. Planning to do more descriptive observation over first month when I am working full shifts. Then become more focused in on specifics of dying as they present in the nursing home. Spradley (1980) suggests this! Very much feeling my way despite reading the literature.....but then that is me all over....I don't seem to learn unless I do it!' [fieldnotes 10.7.00]*

As it turned out I was interested to find that it wasn't only what I saw and heard that I began to report, but what I smelt. Nursing homes are notoriously reported as smelling of urine. Although in one of the nursing homes this was sometimes a problem, commonly it was not an issue. However, sometimes one found oneself remarking on the rather sickly smell of air-fresheners.

I wore my own clothes rather than a nurse's uniform. I wore a badge that clearly stated I was a nurse researcher from the Hospice. When a resident or a relative approached the staff member I was with, the nurse/carer would introduce me; either the nurse or I would explain my position and the project that the nursing home was undertaking.

A small notebook (like a reporter's notebook) served as a quick jotting pad for particular incidents that I came across. Often, however, there would be little time to make an entry except when I was back in my car at the end of the shift. Occasionally I took the opportunity of quickly recording a word or phrase so that my memory would be triggered later on in the day when field-notes were completed. The field-notes were written up either the same day or the following day so that events were still clear in my mind. There were occasions when I just made rough notes because of other pressures. The written-up notes were kept in an A4 book. As I became more confident in recording what I was observing, so the writing of field-notes changed. Instead of just writing and reflecting on each aspect of observation, I started to use the notebook differently. To begin with I had written on both pages; now I wrote on the right hand page of the book leaving the left-hand page blank. This allowed space to add further reflections. A margin on the far left hand page was there to capture themes arising out of what I was observing.

There is a danger for the person observing an incident to too easily assume something about a situation without checking it out. To help me attain a constant reflexive mode (Taylor & White 2000) I stuck 'reflexivity' notices to the side of my computer screen. An example from my fieldnotes illustrates the importance of such reflexivity:

> *"I went over to the right hand side of the bed since Clair was positioned on her left side and asked how she was feeling. 'Better' she replied quietly and shut her eyes. As I stood there I was struck by the newspaper under her bed, the fluff on the carpet, and the general plainness of the room. As I went into the en-suite toilet I noticed the freesias I had thrown away on Monday still in the bin. I felt upset that no-one had changed them – was this further evidence that people might be withdrawing? Later, I bumped into Jan (domestic) in the corridor carrying a load of clothes to the laundry and followed her in. Quite casually I asked her if she knew who it was who normally changed the bin in Clair's room? "Oh! that's normally me and Sheila. However Sheila is working in the kitchen while the assistant cook is on holiday. I am finding it hard to go into Clair's room.....she reminds me of how my husband looked after he had died." Jan then poured out the whole horrific story of how her husband had died 2 years previously from a heart attack and how she couldn't get the ambulance quick enough. Immediately I realised that I had totally assumed the wrong thing. It wasn't that people were withdrawing because Clair's dying had gone on for so long. Here Jan was caring so much that she was identifying the situation with the death of her own husband, and now found it difficult to go in the room. It felt good to be asking Jan about the situation rather than just assuming that I was right and feeling angry that no-one cared enough to clean the room. [Fieldnotes: NH1: 06.09.00]*

Such reflexivity is an important aspect of rigour in research and has been discussed in the previous chapter (see section 3.2.1).

Although in qualitative research Spradley (1980) talks about continuing observation until saturation, that was not my intention. I was more interested in using my observation and fieldnotes as a way of constructing an evaluation of how current end-of-life care was being practised within the setting of the independent nursing home. It is almost impossible to account for the number of hours I spent in the nursing homes. Over the three years being of my involvement with NH1, NH2a and NH2b, I was in a nursing home on average twice a week; this might be for as short as a one hour meeting with the nurse manager or as long as three hours as I helped when a resident was dying. At the end of my time in a nursing home, my written fieldnotes were transferred from my A4 book and typed into a word document for ease of withdrawal and retrospective analysis (see Section 4.5). In total, there were 290 typed pages to my fieldnotes.

4.4.3 Interviews

In order to pick up on issues highlighted by the focus groups and what I was observing as I helped alongside the staff in the nursing home, interviews (Mason 1996) were undertaken with key people[31] involved with the care of a resident who was dying. Prior to the study it had been my intention to try to interview dying residents themselves. However, this changed as a result of the exploratory phase of NH1. At this point in the study, many of the staff in NH1, including the matron and the managers, were focused on a younger woman (65yrs) who had advanced cancer and whom they thought would die in the next few weeks. It seemed that because the resident had cancer greater emphasis was being given to her imminent death. This particular resident was quite articulate and agreed to speak with me about her care as part of the study. However, having deteriorated considerably, her deterioration then 'plateaued'. Because of this, I felt obliged to remain in the exploratory phase until she died. As it happened, it took a further couple of months for this resident to die. Although this was a very useful period

---

[31] Key people were identified as those involved in caring for a resident when they were dying and included matrons/managers, trained nurses, care assistants, GPs, a chaplain, relatives, and a funeral director.

of understanding more fully the differing aspects of end-of-life care in this nursing home, there was a certain anxiety about when the exploratory phase would end and the facilitation phase begin. Secondly, during this 'waiting' time, two other residents in the nursing home died unexpectedly. Both of these other residents suffered a degree of cognitive impairment and at the time of their deterioration were too unwell to be interviewed; the relative 'suddenness' of their deaths made it difficult to plan appropriate interviews during the dying trajectory even if they had been able to participate.

I began to realise that the large proportion of residents in nursing homes had varying degrees of dementia; this made it increasingly complex to interview them. I therefore decided that I would interview the families of dying residents. As I considered the focus of the study, I realised that although it would have been good to interview residents, the focus of the study was more about developing staff knowledge of high quality end-of-life care. Other key people were drawn from both within and outside the nursing home[32]. Interviews were unstructured and tape-recorded for ease of concentration and flow of interview (Mason 1996). The outline for interviewing relatives (see Appendix 4a) remained reasonably constant but there were adaptations of the outline when interviewing professionals (see Appendix 4b), depending on the differing responsibility in end-of-life care. In total, 22 formal in-depth interviews (see Table 4.2) were carried out during the exploratory phase in NH1, NH2a and NH2b.

Most of the nursing home staff had already participated in the focus groups and had seen me working alongside as part of my participant observation; many really enjoyed the opportunity to be listened to. The digital recorder used was small and discreet; when the recordings were transferred to the computer they were very clear to listen to. All interviews were transcribed. Interviews were not necessarily confined to the exploratory phase. Further interviews were carried out in the facilitation phase in order to conduct

---

[32] A focus group (FG 6) was held in NH2a where residents, but not dying residents, had an opportunity to voice their opinions as previously discussed.

formative evaluation on the minor action cycles[33] and in the summative evaluation phase (details of these interviews are reported as part of the evaluation of the major actions undertaken in the facilitation phase in each of the nursing homes – see Section 6.6 and Section 7.4 respectively).

Table 4.2: Number, type and place of interviews

	GPs	**Relatives**	**Resident**	**Care assistants**	***TOTAL***
NH1	2	2	1	2	**7**
NH2a/2b	2	2	-	3	**7**
TOTAL	4	4	1	5	**14**
	Nurses	**NHM/Owners**	**Chaplain**	**Funeral Director**	
NH1	-	3	-	1	**4**
NH2a/2b	1	2	1	-	**4**
TOTAL	1	5	1	1	**22**

4.4.4 Documentary details following the death of a resident

Documentation on the 34 residents who died was collected whilst in NH1, NH2a and NH2b. A pro-forma (see Appendix 5) was made in order to collect as much information as possible concerning the dying trajectory. Once a resident had died, the notes kept by the nurses were scrutinised as to the pattern of deterioration prior to death, the involvement of the multi-disciplinary team, drugs administered and the communication with family members. This helped to build a picture on how a resident had died and the planning that had been undertaken during the dying process. This information became very useful at the collaborative learning groups, and as part of the residents note audit following the piloting of the ICP documentation, when together staff and I critically analysed the care given in the last days of a resident's life.

---

[33] For example: staff 'exchanges' between the nursing home and the hospice; evaluating specific training; obtaining information after a stressful period in NH2a.

4.4.5 Reflective diaries

Reflection on practice (Johns & Freshwater 1998; Gibbs 1988) played an important part in the generation of data and the facilitation of learning for all those participating including myself. The trained nurses in all the nursing homes were encouraged to keep a reflective diary[34]. Tutorials on reflection were given by me to encourage nurses participating in the research process to be reflective. Each nurse was given a journal with Gibbs (1998) reflective model drawn out on the inside cover. Many nurses had not been formally taught about critical reflection as a way of enhancing practice and some found the diaries difficult and quite threatening. The diaries were not for me to look at although sometimes staff spontaneously brought them to the collaborative learning groups (see Chapter 6).

I also kept critical reflections as part of my fieldnotes in order to be reflexive about what I was experiencing, both in undertaking this action research study and in working to develop end-of-life care specific to the nursing home setting. My feelings and my response to what was being said and done within the practice setting were just as important as the other data. This reflexivity helped me in two ways: firstly, to clarify what I was learning from incidents that occurred in *doing* action research; secondly, how the searching of literature to clarify an incident helped me to be more prepared the next time. On one occasion I was challenged by a manager that *'people are different when you have been around - but after a couple of days things settle and we are back to how we normally are' (Fieldnote reflections/diary: p.114. April 2001).* Some of the staff were becoming more confident and more empowered about how they managed end-of-life care, but the project was beginning to upset the status quo. At the time I took the incident very personally as though I was at fault. However, through dialoguing the incident in my diary I gained greater clarity about what I believed to be the real issue;

---

[34] Although I am sure some care assistants could have kept a diary – and this would certainly be a very interesting aspect for further research – at this point in the research I only considered it for the trained nurses.

namely, issues to do with change and power. This is discussed further in a reflexive discussion at the end of Chapter 6 (see Section 6.7.1).

4.5 ANALYSIS OF DATA

In a systematic review of action research studies in nursing, Waterman et al. (2001) discuss the different analytical methods used (see Box 4.4). Thematic analysis was the most common way of analysing data used by the authors. However, the wide range of different analytical methods reported by Waterman et al. (2001) highlight the importance of choosing the appropriate method for the specific situation.

Box 4.4: Different analytical uses in action research[35]

Type of analysis reported:	**No. of studies:**
No analytical information stated:	22 (37%)
Qualitative analysis:	
No specific analysis specified	6 (16%)
Thematic analysis	10 (27%)
Descriptive analysis	1 (3%)
Content analysis	2 (6%)
Means Critical analysis	1 (3%)
SWOT analysis	1 (3%)
Importance Performance analysis	1 (3%)
Analysis of statements of experience	1 (3%)
Category saturation	1 (3%)
Quantitative analysis:	
No specific analysis specified	4 (11%)
Descriptive statistics	2 (6%)
Cost benefit analysis	1 (3%)
Field Force Analysis	1 (3%)

---

[35] Some studies used more than one analytic method.

Waterman et al. (2001) show that out of the 59 selected action research studies, twenty-two (37%) were reported as having no information regarding the analysis of data. The explanation offered for this was that those undertaking the research *'may not have been able or prepared to deal with this aspect of the research' (Waterman et al. 2001: 38).* This would tend to support Meyer & Batehup's (1997) challenge that action research can focus too much on action rather than research. In their review, Waterman et al. (2001) point out that although methods of evaluation were evident, often the way data were analysed was not specified.

In this action research study, data were continually collected throughout the various phases of the study. Analysis in action research is iterative – occurring dynamically in collaboration with those participating in the study. How iterative it is may depend on the experience of the action researcher – the importance of feeding back and clarifying issues became a more natural part of the action process as I gained more experience as an action researcher.

Titchen (2000) in her action research study describes analysis being done both concurrently during the fieldwork and retrospectively. In discussing the analysis undertaken in this action research, I will first describe the concurrent analysis that concentrates on the analysis of data as a result of the process of self reflection and critique during the study, and then the retrospective analysis that was undertaken once a phase of the action research or my time in the nursing home had finished.

4.5.1 Concurrent analysis

Concurrent analysis was carried out as a result of reflection and critique within my methodological and reflexive fieldnotes. As stated above (see Section 4.4.2), my fieldnote diary was divided into three columns where space was given to write alongside initial observations in a further critique of what I felt was happening as a result of further reflection and reading – especially about the methodology of action research. This often resulted in a critique of my actions, and the feeding back of ideas about the study to staff and managers in order to check out suitable ways to take things forward in the action research.

4.5.2 Retrospective analysis

A retrospective analysis of data was undertaken using a variety of analytical methods during or following the different phases of the study. The qualitative data were analysed using thematic analysis and qualitative content analysis (Flick 2002). The quantitative data were analysed using descriptive statistics.

i) Thematic analysis

During the exploratory phase in each of the nursing homes, a qualitative assessment describing and interpreting how end-of-life care was being managed in the nursing home, and the staff's reaction to it, was undertaken. For this phase, where an ethnographic approach to assessment was used, a thematic qualitative analysis (Flick 2001) was undertaken. Data from the focus groups and interviews were transcribed. Although the transcribing of tapes can be considerably time consuming (Lofland & Lofland 1988), doing the transcribing myself enabled me to start the analytical process. The transcripts of focus groups and interviews were examined and details of initial open coding carried out by highlighting bits of text at the side of the transcript. Dey (1993) calls this 'annotating the data'. The process of analysis is in the first instance the 'breaking up' of data. Dey (1993) uses the idea of the breaking of an egg prior to making an omelette to explain the importance of *'resolving data into its constituent components, to reveal its characteristic elements and structure'* (Dey 1993: 30). An A4 sheet of paper was designed to act as a summary to this initial analysis and was adapted from Miles & Huberman (1994). These sheets gave the type of contact (interview/focus group etc) and contained three columns detailing the salient points of the record and their associated themes; a column detailing the page number was made for ease of retrieval by hand (see Appendix 6). Subsequent selective coding was carried out and gradually, major themes became apparent. Data from fieldnotes was also included in this analysis and helped to build as complete a picture as possible of end-of-life care in nursing homes. This data is reported in Chapter 5.

ii) Qualitative content analysis

In NH1 following the implementation of the 'collaborative learning groups' qualitative content analysis (Rice & Ezzy 1999; Flick 2002) was undertaken from ten tape-recorded sessions in order to demonstrate and describe the different ways knowledge about end-of-life care was being gained by those taking part. Qualitative content analyses uses categories that are *'brought to the empirical material and not necessarily developed from it'* (Flick 2002: 190). Categories examining the different ways staff gained knowledge about end-of-life care (being taught, developing mutual understanding, and critically analysing situations) were brought to the data; the data were then examined for examples of these specific categories.

While examining the texts of the ten tape-recorded sessions for these categories on gaining knowledge, I became aware that the 'collaborative learning groups' were also providing support and communication between staff. This was confirmed when reading the evaluation questionnaires (see Appendix 8) returned by staff as part of the summative evaluation. So, in analysing the 'collaborative learning groups' both content analyses and a thematic analysis were used. These data are reported in chapter 6.

iii) Descriptive statistics

In NH2b, following the implementation of the integrated care pathway for the last days of life (ICP), descriptive statistics were used to analyse documentary evidence in relation to critical aspects of care in the last days of life. Care given as a result of using the ICP documentation was compared to that which had been given prior to the implementation of the ICP. These data are reported in Chapter 7.

Analysis of the summative evaluation questionnaire in each of the nursing homes was also undertaken using descriptive statistics.

4.6 ISSUES OF INFORMED CONSENT AND CONFIDENTIALITY

Other ethical issues involving action research have been discussed in the previous chapter in Section 3.4.2. This final section discusses the ethics of informed consent and confidentiality in relation to this study.

4.6.1 Informed consent

In action research, because the focus of a study may change, it is difficult to state prior to stepping into the fieldwork exactly how the course of the research will run. Meyer (1995) argues that requesting participants to sign up to a piece of research where what is to be undertaken is not yet clear could be an infringement of consent. At the commencement of the study in each of the nursing homes, nurse managers/owners were asked to consent to the main aim of the study with the knowledge that how practice would develop would need to be discussed further following the exploratory phase (see Appendix 2b).

In an attempt to be as transparent as possible about the research and its intention, an information sheet was clearly pinned to the notice board in the staff rooms in the nursing homes. Next to this there were two envelopes – one contained a handful of empty consent forms while the second was there to collect completed consent forms. However, as the study progressed, it felt increasingly inappropriate while sitting around in a group discussion to invite new staff sign a consent form; in these situations, consent was given verbally and new staff were given the option to formally consent. There was therefore this on-going process of consent (Meyer 1993), explaining the study to new staff as they arrived to work in the nursing home. It was in many ways difficult for staff not to take part (Kelly & Simpson 2001), especially when an action cycle became part of the development of practice in the nursing home. One person, however, requested formally to come out of the study during the facilitation phase in NH1.

However, for those people being interviewed who were outside the immediate nursing home environment, such as GPs and relatives, I felt it necessary to get written consent. In the main, although not truly within an action research approach, I felt there was an expectation for more formal consent from these key people who were not actively involved in the nursing home on a regular basis. When approaching relatives, or indeed the residents for the resident focus group, it was the nurse manager of the nursing home who, on my behalf, contacted relatives or resident/s regarding an interview and asked them formally to consent to take part. No-one who was approached ever refused to take part. They were all extremely interested in the study and wanted to help in any way they could.

As can be seen from the discussion, gaining consent in collaborative research poses different issues to that of a positivist paradigm (Dawson & Kass 2005). In gaining consent to observe and take fieldnotes when 'helping out' alongside staff in the nursing home, it was important that residents understood about the study and why I was around the nursing homes so much. It was discussed with the owners of NH1 whether each resident and their family should be told formally about the action research study in a letter. However, in the end it was decided that I or the nurse manager would inform residents and their families as appropriate throughout the course of the study. As has already been explained in Section 4.4.2, I did not conceal who I was or where I was from. However, it would have made it very difficult if whenever I was working alongside a staff member the research had to be explained or a consent form signed. As Parahoo (1997) explains, one cannot become part of the furniture if one keeps asking the person who is being observed if they can sign an informed consent.

There is increasing interest in informed consent and collaborative research. Flexibility in gaining informed consent would appear appropriate (Hyder & Wali 2006: Dawson &

Kass 2005). However, there is some evidence that, even within a collaborative approach to research, the formality of gaining informed consent in some situations helps to create and maintain communication about the research (Dawson & Kass 2005).

4.6.2 Confidentiality

Specific ground rules that participants agreed to when taking part in a focus group or interview assured that confidentiality was maintained. Respect for colleagues in the group and their opinions over issues was stressed and individuals were asked not to disclose aspects of the discussion that had occurred in the focus group. It was important that participants felt they could speak freely, and genuinely engage with the discussion.

However, negotiating rules about the confidentiality and anonymity in action research is not necessarily as straightforward as it is with other approaches. Because of the length of time over which the action researcher is involved in the setting, and because of the informality that can occur when participating alongside practitioners in the field, stringency around the confidentiality and anonymity is in danger of becoming relaxed. Williamson & Prosser (2002) raise the important question as to whether confidentiality and anonymity can ever be guaranteed in action research. Although I ensured that all identity of individual comments was avoided when feeding back data, I was not confident that all staff in the nursing home, the majority of whom were not used to participating in research, took on this responsibility. At one point in the study, I realised that much of what was being said in the collaborative learning group work in NH1 was being reported back to management. This had a detrimental effect on relationships between staff and the management of the nursing home. In trying to address this breach of confidentiality with management, it was obvious that management felt otherwise. Staff were remarkably tolerant of the situation but confidentiality had been breached and I felt very responsible. All names used in this thesis are fictitious.

4.7 CONCLUSION

In this chapter I have given an overview of the approach to this action research. As I have already stated, researching practice is 'messy' (Schon 1987). As a journey, it was considerably more problematic than the seemingly straightforward account given in this chapter. As Ladkin (2004) wisely states:

> *"Perfect 'action research' cannot exist. At its root is the unpredictability and confounding nature of human beings and our systems." Ladkin (2004: 547)*

Nonetheless, I have explained how the nursing homes taking part in this action research were selected and the three different phases whereby together with the staff we were able to explore issues about end-of-life care in the nursing homes, plan appropriate action cycles, and analyse and evaluate the effect of the cycles undertaken. I have discussed the various methods used to generate data and how those data were analysed.

The next three chapters report the findings of this study. Chapter 5 reports the qualitative analysis from the exploratory phase, while Chapter 6 and Chapter 7 are devoted to recording each of the major action cycles in which staff in the nursing homes were involved during the facilitating action phase. An analysis is undertaken on what is reported in each of these chapters. At the end of each chapter there is a 'reflexive discussion'. These reflexive discussions draws attention to two different issues. One issue is related to a theme about end-of-life care in the nursing home that I felt was significant as I reflected on what I was learning, and this theme makes a link to the following analytical chapter. The second issue is related to my reflections on the process of undertaking action research[36].

---

[36] These reflections are framed by the three major features of action research according to Meyer:

- participation
- democratic impulse
- the simultaneous contribution to social science and social change.

CHAPTER 5

THE CONTEXT OF THE STUDY NURSING HOMES

This chapter presents the findings from the exploratory phase examining end-of-life care within the context of the study nursing homes (NH1 and NH2a). McCormack et al. (1999) highlight the importance of practice development facilitators understanding the context of an organisation prior to formulating any change strategy. Context is referred to as 'the environment or setting in which the proposed change is to be implemented' (Kitson et al. 1998: 150).

The context of any healthcare environment is complex and independent nursing homes are not excluded. Kitson et al. (1998) characterise the context as having three main areas: the overall culture of an organisation and the way things are 'done around here' (Manley 2000) which would include the way care is managed, whether 'task driven' or person-centred (Saunders 1987; Kitwood 1997), and aspects of continuing education; secondly, relationships within the organisation including differing leadership roles and effective teamwork; and finally, the organisation's approach to effective evaluation including formal measurement such as audit but also the importance of user feedback, and practitioner reflections (McCormack et al. 1999). Staff working in nursing homes are often very committed to the work they do and form close relationships with their residents (Hanson et al. 2002). However, there is evidence that relationships between staff and management within the homes appear fragile, highlighting problems of conflict (Forbes 2001; Walker et al. 1999). Poor staffing and low morale may be linked with a clash of values between staff and management (Kayser-Jones 2002; Deutschmann 2001).

It was therefore important not only to understand current practice in relation to residents dying in the nursing homes and the pressures faced by staff in end-of-life care, but also to identify factors within the nursing home organisations themselves that might militate against development of that practice.

The aims of the exploratory phase in each nursing home therefore was to examine the home's context including its culture, and leadership styles, in relationship to end-of-life care; to bring to light the difficulties as well as the satisfying aspects that staff experienced when caring for dying residents and their families; and to collate this information and feed it back to staff in order that we could decide how they wanted to develop end-of-life care in their nursing home.

After a brief description of the study nursing homes in relation to their organisational structure, dependency levels and number of deaths, this chapter presents the contextual and clinical issues in the homes that were seen as potential barriers to developing quality end-of-life care. The end of the chapter provides a reflexive discussion on how these issues were fed back to management and staff in the nursing homes and how they made decisions about what they wanted to take forward as 'actions'.

5.1 THE STUDY NURSING HOMES

NH1 and NH2 were both well-established independent nursing homes. Both NH1 and NH2 were adapted from large residential houses with newer extensions. A large number of residents in both homes were self-funded[37].

---

[37] At the time of the study, residents who had over £15,000 capital were obliged to use up their capital before social services paid for care. Private nursing homes rely on a number of 'fee paying' residents in order to be able to give a higher standard.

NH1 was a small (less than 35 beds), privately owned nursing home and cared for frail, older people, registered for the following categories of care: chronic illness including physical disability in residents over 60yrs of age, mild/moderate dementia with no behaviour disturbances, historic terminal care status[38] and respite/convalescent care. The owners of NH1 took pride in their nursing home and one of them specifically explained the changes that had been made since they had taken over the property eighteen months previously. Both owners were in the home every day and often at week-ends. The nurse manager had moved with the owners from their previous care home (residential). She had worked as deputy matron for the 12 months following the move before taking responsibility for the nursing care for the 6 months prior to commencing the study. NH1 had a regular art therapist, and paid for a private physiotherapist to come into the nursing home for music/movement on a weekly/monthly basis. They also organised various musicians to play/sing with residents.

NH2 was a medium sized nursing home. It was part of a non-profit making organisation, which also catered for a large sheltered housing market as well as two nursing homes and a residential home. NH2 did not have historic terminal care status but had an award for care given to residents with dementia. Similarly to NH1, the nurse manager had only been in charge of the nursing care for the previous 12 months. The accommodation of NH2 was on two floors. A third floor had at one point been used as a rest area for relatives staying overnight when a resident was dying. Due to a reorganisation of accommodation however, it was being developed into a couple of staff rooms. In NH2, a part-time activity co-ordinator employed by the organisation facilitated one-to-one work and reminiscence groups with residents suffering from varying degrees of cognitive impairment, as well as organising a variety of other work (literature/current affairs groups etc.) with those who were not cognitively impaired.

---

[38] This category used to exist in order that residents who were expected to die could die in the nursing home and not be taken to hospital when their condition deteriorated. It was specifically allocated to nursing homes geographically positioned a long way from city centre hospitals at a time when residents were transferred to hospital to die. It meant that elderly relatives did not have long distances to travel in order to visit.

There was a social club once a week for 'able' residents to mix with other residents from the organisation. The staff of NH2 used the physiotherapy service funded by the primary care trust specifically for the independent nursing home sector.

In both nursing homes, domestics and cooks were included as part of the caring team. Domestics would chat to residents every day while cleaning the rooms and automatically built up a relationship.

The level of dependency of residents within the nursing homes was fairly high. A global holistic score of dependency that underlines basic dependency-activity-quality staffing strategies (Hurst 2003) was recorded in each nursing home within the first month of the exploratory phase. In dependency level 1, residents required little help; dependency level 2 required assistance from one member of staff to wash, dress and help with toileting because of mental frailty; dependency level 3 residents were dependent on care assistant or nurse because of their advanced mental frailty and/or increasing physical frailty; and in dependency level 4, residents were reliant on two members of staff for all their needs and the majority required help with eating and drinking. Table 5.2 shows the large number of residents in dependency level 3 and 4.

Table 5.2: Level of resident dependency in nursing homes

Nursing Home	Dependency level 1	Dependency level 2	Dependency Level 3	Dependency Level 4	TOTAL No. of residents (%)
NH1: No. of residents	1 (4%)	4 (16%)	11 (44%)	9 (36%)	25 (100%)
NH2: No. of residents	-	6 (15%)	21 (51%)	14 (34%)	41 (100%)

Care assistants shouldered considerable responsibility for these residents, and nurses were reliant on the care assistants' ability to communicate residents' problems to them.

> *'I would say at the moment we have so many [residents] that are high dependency and very, very few 'one man' residents.' [CA. FG1, pg.11]*

A majority of residents in both nursing homes in the study were suffering from either a form of dementia and/or vascular disease (see Table 5.3). Less than 10% of residents had a formal cancer diagnosis and in the majority of cases, the cancer diagnosis was of secondary importance to the reason for admission. There were a number of occasions when a cancer was suspected but not investigated because of the mental frailty of the resident.

Table 5.3: Main diagnoses of residents[39]

	NH1 (n= 25)	NH2 (n=41)
Cardiac disease	**2 (8%)**	**5 (12%)**
Dementia	**7 (28%)**	**21 (51%)**
CVA/stroke/vascular disease	**9 (36%)**	**3 (7%)**
Parkinson's disease	**1 (4%)**	**1 (2%)**
Diabetes	**2 (8%)**	**2 (4%)**
Old age frailty including blindness	**4 (16%)**	**6 (14%)**
Arthritis	**1 (4%)**	**8 (19%)**
Diagnosed cancer	**2 (8%)**	**4 (9%)**

There was a total capacity of 66 beds across both nursing homes. During the three years of the study 41 residents died. Five of these deaths occurred in hospital. During the action research in NH1 (25 beds), which continued for one year, sixty-one percent of residents died. In the first year in NH2, where capacity was 41 beds, thirty-seven per cent of residents died. Increasingly in nursing homes, a majority of residents die within two years of admission (Sidell et al. 1997).

---

[39] Most residents had more than one medical diagnosis but only the main medical problem/s for which admission to a nursing home was instigated is given.

5.2 CONTEXT ISSUES IN MANAGING END-OF-LIFE CARE IN NURSING HOMES

Despite the increasing frailty among residents admitted to nursing homes and the subsequent increasing number of deaths, the minimum staff-to-resident ratio remains unchanged at 1:5 since staffing standards were first set in the early 1990s. Research highlights inadequate staffing (Walker et al. 1999; Kayser-Jones 2002) but the changing role of nursing homes from that of a rehabilitative model to a more palliative care model remains unrecognised (Hanson et al. 2002) and has put increased pressure on staffing. There is no doubt that the day-to-day work in nursing homes is hard and heavy with the majority of residents requiring two people to help them get up. Hughes et al. (2005) have argued that residents dying of advanced dementia need as much care and as much specialist input as is currently being given to those dying from advanced cancer.

I now present the more detailed results of the exploratory phase, which highlighted aspects of organisational management in the nursing homes that were likely to act as barriers in the development of quality end-of-life care.

5.2.1. Models of care organisation in the nursing homes

Nursing care in the study nursing homes was organised around various nursing care models. Using the typology cited by Titchen (2000), these consisted of all three categories of nursing care: traditional nursing; individualised nursing; and, patient-centred nursing. In NH1, the day-to-day care was modelled around a 'traditional nursing' approach. Here, care was focused around the physical care given to residents and getting through the work. Unusually, the management in NH1 had decided on a 1:4 staff-to-resident ratio instead of the regulated ratio of 1:5. The care for dying residents included excellent physical care but lacked attention to the psycho-social-spiritual aspects around death and dying. In this home, a dying resident would be 'checked on' every ten minutes by a member of the care team.

> *'I give each carer a time to go in during the hour – one will check the resident at ten past the hour, another at twenty minutes past the hour and so on. I go in on the hour. In this way it shares out the care.'(Nurse manager interview, NH1, pg.11)*

Some care assistants took it upon themselves to stay and sit with a resident, especially during the night if they were not busy, but this was not policy. This emphasis on tasks and 'getting the work done' formed the basis to the routine in NH1. On one occasion the nurse manager and I had just finished "doing the residents' top half and getting them up for breakfast". As we walked into the office she commented that we had "lost half an hour" of the morning's work:

> *'Because we were 10 minutes over time with the night report this has wasted time on the floor….." I asked for clarification of how she saw things... "ten multiplied by the six staff on this morning equals 60 – 60 minutes of time wasted.' (Fieldnotes: 12.09.2000)*

Time within the independent nursing home sector equals money spent, and is often in direct conflict with the way staff want to work. The nurse manager was extremely conscientious; however, it felt as though concentrating so much on 'getting the work done' eclipsed the needs of her staff. On this occasion there was no acknowledgement of the importance of the night nurse's report; just the fact that time had been wasted. This more traditional 'task orientated' approach to organising nursing care, established to protect the untrained carer from anxiety (Menzies 1960), could be seen as a model for nursing homes because of their largely untrained workforce. However, here in NH1 nurses said that they wanted to be given more responsibility.

> *'[The nurse manager] does too much. She doesn't need to do it…. You end up thinking….we're…..not wanted.'[Fieldnotes NH1, 13.11.2000]*

Both nurses and care assistants were very capable but they themselves often said they did not get recognition for the work. It was not that the nurse manager did not appreciate the work; she did. Once, when I was asked to go with the nurse manager to see a resident who was dying, she remarked to me how the care assistant that morning had suggested putting the resident's photographs by the side of his bed. *'I thought that was a* *nice idea' [NM fieldnotes, 10.11.2000]* was her comment about the care assistant's action. However, staff rarely got this affirmation.

Nursing style in NH2a

The nurse manager organising the care in NH2a did things differently. A feature of the care was the nurse manager's insistence on a 'person-centred' approach, with care being modeled around resident autonomy and dignity. This care model has been compared to that of the palliative care approach (Hughes 2005). In NH2a, residents had their own 'key workers' and 'named nurse' to emphasize the individuality of residents so that residents' particular needs could be more easily met. The values-base that underpinned this nurse manager's attitude towards end-of-life care was immediately apparent.

> *'[Besides the physical care] the psychological care - letting people talk about death and dying - is really important, if they want to.... The spiritual care is very important. I differentiate you see between the religious side and the spiritual side...I think people can have a spiritual side and have no church foundation if you like. Where I was before we were a wee bit further developed in that if we knew people particularly liked poetry or certain types of music, or flowers – things like that – then, whoever was sitting with them would perhaps read some of the poems or even play some of the music...' [Nurse manager interview, NH2a: 15.05.01, pg.3]*

Not only was the holistic care of residents important but staff were also given equal attention. Power was more equally shared between the workforce in NH2 with care assistants taking responsibility as key workers. This nurse manager took pride in knowing well all her residents but was able to devolve responsibility to staff for the actual day-to-day care. However, even with a less traditional nursing approach, staff still found it difficult to sit with residents when they were dying.

> *'...they used to actually have somebody day and night at that person's bed. It wasn't necessarily [always] the same person, you would take turns..... and it was nice. Because you knew the person wouldn't get forgotten about in the room, which is quite easily done now that it's not happening.' [CA. FG3, pg.2]*

After a year in NH2, a new nurse manager arrived and the care model changed to an 'individualised nursing' approach where the manager was not so involved. This style of management had what Titchen (2000) calls a semi-professional ethos, where practice was nursing-centred rather than based around a medical model, but where advantages for the nursing home over-rode the needs of the resident.

The disruption caused to staffing by the different nursing model imposed by a new nurse manager was considerable and was to become a major cause of staff leaving (see Chapter 7). New nurse managers would bring their way of working. In NH1 where there had been a previous person-centred model of care, the new incoming nurse manager imposed a model she was familiar with – a traditional approach to care. This sudden change of care ethos could well have been what was behind thirty-six staff leaving prior to the start of the study in this nursing home. The owners had hoped no further staff would leave. To my knowledge, a further four staff left during the study and by the time the study finished, the number of *original* staff remaining was less than six (12%).

Instability of staffing in care homes is well documented (Redfern et al. 2002) but in both NH1 and NH2 much of the staffing instability coincided with the change in nursing leadership.

5.2.2 Under pressure, time constraints and low morale

The staff in both of the nursing homes were under pressure with the amount of care to be carried out. This was a constant source of difficulty and frequently mentioned in NH2 where there was a 1:5 carer/resident ratio.

> *'I find that we never have enough time, because there isn't enough staff. I think that that is a big problem. You know what you want to do and need to be done but physically you don't have the time.' [CA. NH2a, FG3. pg.10]*

The staff-to-resident ratio is set at a minimum of 1:5 by the Care Commission. This is despite an increasingly dependent population in nursing homes. However, NH1 routinely provided a 1:4 carer/resident ratio in the hope that sickness/holidays would be covered without having to employ agency staff. Staff there did appear less pressurised.

When there were a number of ill/dying residents, staff in NH2 found the constant pressure of staff shortages very stressful especially when it involved compromising care when a resident was dying.

> *CA1 '....but I was constantly having to make a choice whether you dealt with the ones who were seriously ill or you dealt with and helped the other residents with the things that you normally helped them with. I certainly couldn't manage...I couldn't manage.*
> *CA2 I think that was down to staffing levels because of the shortages of staff and the number of agency nurses that were being brought in.*
> *CA8 Very stressful'.* *[CAs.FG3, pg.4]*

Both nursing homes had a 'pool' of staff that they could call upon but even this was not enough and 'agency' staff were required especially at weekends. A period of reasonable stability in NH2 was achieved a few months after I first started there but when the nurse manager left nine months later, considerable problems of instability resulted.

There was a danger that lack of regular staff would affect morale. Staff often offered to work extra shifts to help out if the home was short of staff, in order to avoid having agency staff. But when this went on month by month and sometimes with little acknowledgement of the value of their extra work, morale would plummet. There appeared to be a correlation between morale, lack of staff and the heaviness of the work. If one staff member was 'low' it seemed that others were then pulled into what seemed a downward spiral.

> *'...Morale is so low here at the moment with the lack of staff ......even if the management said 'well done' sometimes, or 'thank you' for doing an extra shift. We're just expected to accommodate.' [CA, NH1: fieldnotes:19.09.00]*

There was a constant talk about lack of funds, especially in NH2, and it was evident that staff and management felt money was wasted in having to employ agency staff who, because they did not know the residents or the routine, were seen by all as being less efficient than regular staff. Nurse managers did try to get regular agency staff in order to combat this. However, despite management trying to come up with incentives to recruit staff, instability was still a problem. The difficulties of staff turnover were not just in nurses and care assistants working 'on the floor'. During interviews, GPs often spoke about the high turnover of nurse managers in the care homes. One GP pointed out that NH2 had had three nurse managers in the last five years.

> *'There's a fairly high turnover for lots of reasons and I am sure I couldn't begin to know them all. But there is a high staff turnover even amongst the senior nursing staff, which you might expect to remain. I have seen three come and go in 5 years - matron type people...... So I think big issues of staff [are a major difficulty]. And as for the rest of the staff they change every 5 minutes as far as I can see! You go in there and there is someone different every time.' [GP3,13.06.01*]

NH2 was to have a further two new nurse managers within the lifetime of the study. This made it difficult for GPs who themselves found it difficult to balance all the care they had to give in the community alongside nursing homes; nursing homes were often another thing for GPs to have 'to juggle' with alongside their other day-to-day work. GPs gave higher priority to older people still living in their own homes. For those in nursing homes, they felt there were nurses on site.

Many of the GPs interviewed said that the nurse manager of a nursing home was key to its success. It was the person in charge of nursing care who set a good or not so good standard of care and was able to influence morale. In particular, one GP commented:

> *'I suppose the main thing in the nursing home will always be the nurse in charge and his or her attitude disseminates down to all the staff. The nursing homes I see as 'not so good' nursing homes providing 'not so good' care are usually those with a high turnover of staff and temporary staff and bank staff....a lot of other trained staff coming and going. Again it is back to continuity of care. It is patients not seeing the face that they know at a time when they are vulnerable and perhaps most need to see a familiar face.' [GP1, 25.08.00]*

GPs genuinely respected the work that both care assistants and the nurses tried to give in the nursing home but could understand that staff didn't stay long because their salaries were so low. At the beginning of the study some care assistants were earning £3.90 an hour. However in conversations with staff 'on the floor' money was not the reason for staff leaving.

> *'[NH owner] told me how the staff had had their salaries raised by one pound an hour since the Denhams had left. Interestingly, only eight out of the original staff had stayed so I wasn't convinced that money was the issue.' [Fieldnotes, 16.05.01]*

Most care assistants in both nursing homes worked because they wanted to help older people and wanted to do a good job. They wanted management to value the work they did with the residents. However this required managers to shift their assumptions that *"these people cannot do anything else, which is why they come to work in nursing homes". [NH owner, fieldnotes: 22.02.01].* If staff were not able to give residents the time or felt that management did not really value the work they did, it appeared to exacerbate low morale and became a reason for staff leaving.

5.2.3 The need for a culture of learning

NH1, with a more traditional approach to nursing care, had little learning culture. Any new teaching of staff was done by the nurse manager being sent off on a course and returning to teach the rest of the staff. There was an apprehension that increasing staff knowledge might be an incentive to 'better themselves' and move on.

> *'That's why we don't run courses. No sooner someone gets a qualification they are off.' [NM, fieldnotes, 21.09.00]*

The owners nonetheless admitted that during their 17 years' experience of running nursing/resident homes, staff mostly only stayed about 18 months, and because of this, any training was seen as a waste of time and money. This confirmed GPs' comments about staff changing 'every 5 minutes'. By sending the nurse manager on a course, training stayed within the nursing home. Nevertheless there was a genuine interest in 'trying to make things interesting for the girls' [Nurse manager, fieldnotes, 14.09.00]. This 'making things interesting' took the form of practical demonstrations of certain procedures such as catheterisation, the taking of blood sugars, and the use of a stethoscope to listen to a resident's breathing. The relevance of these things to the enhancement of care assistants' skills was debatable.

On one occasion in the staff office of NH1, an *agency* care assistant was talking about her SVQ training. Staff were suggesting that if a nursing home was well known for educating their staff even if people left (after doing a course) the home would still attract others. The nurse manager did not agree. As the conversation continued, different staff present suggested different solutions to this staffing problem: staff being obliged to stay at the nursing home for a certain period after the course, having to pay back the cost of the training, or the home having a policy where staff work for a year in the nursing home before being sent on a certain course. There was a sense that none of this had been discussed before. NH2[40] had a specific educational budget and many staff went off for particular study days (such as understanding stroke, dementia, mouthcare) they wanted to attend. However, there was no framework for who went when. Certain staff who were more vocal about going on study days got what they wanted but there was no requirement to report back what had been learnt.

The idea of nursing 'handovers' being used as a way of stimulating learning within a nursing home was only encouraged by the nurse manager leading the care in NH2. While she was leading the team, there was a very comprehensive handover for both morning and afternoon shifts for all staff and I was impressed by the camaraderie amongst the staff after the hard morning's work. I was conscious too that as nurses and care assistants reported back together over care given, another factor was present. In reporting back staff felt proud about the care they had given and this in turn made them feel valued. There was discussion together about what might be the cause of a certain issue with a resident and the consequent discussion about what staff thought was the best solution. Unfortunately this was to change shortly after I arrived. The organisation needed to 'save money'. However much the nurse manager of NH2 on insisted the importance of the handover, she was eventually undermined when the nurse manager of the other nursing home in the organisation agreed to the idea of a limited handover[41].

---

[40] NH2 being a not-for-profit organization meant that some of the organisation's profits went into an education budget.

[41] I was later to learn that this other nurse manager came to regret this decision.

In the main there was little recognition that handovers were an opportunity for learning and support. Top management saw a formal handover by staff as a luxury, not a necessity. Even though care assistants did the majority of the caring, they were not asked to report back formally. This reinforced the idea that care assistants were not valued for the work they did. If care assistants did not see their work as valuable then there was a danger that they would not value the importance of education and a learning culture.

The lack of formal handovers being used as a learning opportunity not only prevented in-house discussion/reflection on care but also affected staff communication. On some occasions, staff found out by chance about a death that had happened only by realising the resident's room door was locked or worse still, as happened on one occasion, meeting a relative clearing the room. Many care assistants found this upsetting and felt let down, especially after forming close relationships nurtured over months/years.

> *CA8 'Sometimes you don't know until you go into their room and they are not there.*
> *CA1 You go to the door and it is locked and it's like...*
> *CA2 Nobody told me.*
> *CA3 Sometimes you walk in...*
> *CA8 Yeh!*
> *CA1 ...and you have been off for a few days and you...*
> *CA8 ...to talk to them and they have passed away*
> *CA1 ...you go in...because other people have been there [in the home and] they presume you know.' [CAs.NH2a, FG3, pg.20]*

Following formal feedback of the exploratory phase and emphasising the poor communication over the death of a resident, the nurse manager in NH2 was able to insist on a handover for all staff coming on the late shift. The compromise was to exclude the direct reporting back of individual staff from the morning shift. The nurse manager left shortly afterwards and then the handover time was cut further to include only the trained nurse coming on duty. Because the home was often very busy, once care assistants were out on the floor it was often difficult to ensure that they had all the information they required.

This lack of support and a learning culture is not an uncommon feature in nursing homes (Hanson et al. 2002). Such a situation however has the potential of negatively impacting on a practice development initiative.

5.2.4 Staff support and teamwork

Caring for the dying is one of the most stressful aspects of care that staff have to cope with in nursing home work, especially for young care assistants. Young people are attracted to nursing home work often from a desire to help older people – getting them washed and dressed, brushing their hair, and even taking them out to visit places – with what might be seen almost as a 'Barbie-doll' approach to care. However, work in nursing homes is very much more demanding. Gone are the days when residents admitted themselves to a nursing home for companionship. Nursing homes are now becoming the place where older people die (Teno 2003). But caring for a dying resident was never mentioned as part of the work when nursing home managers were interviewing new recruits. With the difficulty of recruitment, nursing home managers were looking to fill vacancies; not put people off by mentioning dying.

In one situation in NH1, the nurse manger had asked an experienced carer if she and the young new carer would like to give a bed bath to a very frail resident unlikely to live more than a few days. The new carer appeared to really enjoy being involved but the following extract from my fieldnotes underlines a young carer's vulnerability.

> *'After the bed bath, the care assistant and I were speaking together - answering questions that the new carer posed. The conversation covered Grace's*[42] *frailty and the fact that she might not have long to live. The new care assistant suddenly burst into tears. C/A Diane was superb at supporting her, encouraging her to cry if that is what she wanted. ……. All three of us moved to sit and chat in the nearby sitting room that was empty. We chatted on as the new carer regained her composure and soon she was describing a programme she had seen on TV the previous night about cancer. As we chatted the nurse manager joined us. "Yes, but people die all the time. It's a matter of accepting and getting on with it," she added…' [Fieldnotes, 9.11.00]*

---

[42] All names used in this thesis have been changed.

The last abrupt piece of advice was insensitive and I hoped that the support that the care assistant had given might have been enough to overcome its subsequent effect. However, this new trainee carer never returned to the nursing home, as I was to find out a few days later:

> *'Yes, [she] never came in…she said she'd had a rough night. We can't take people on who aren't reliable!' [NM comment, fieldnotes, 10.11.00].*

Without appropriate support of young care assistants entering nursing home work, the difficulty of recruitment is likely to persist. Another care assistant in the study explained how she had handed in her notice after experiencing her first death when first working in a nursing home – she found it so shocking and was totally unprepared, not realising that that sort of thing happened in nursing homes. Many spoke about the first death they witnessed.

> *'Death isn't something you've faced before you come and work here……I never thought I would be dealing with dying when coming to work in a nursing home ….. to think a death has happened in a building that you've been in is terrible.'. [CAs.FG4, pg7]*

Lack of support and a lack of insight into the needs of more sensitive young care assistants coping with a resident who dies was clearly a reason why care staff left nursing home work. However sensitive other colleagues might be, without a culture of support around end-of-life care from management, it may be difficult to retain new recruits.

But it was not just new, young care assistants who needed support. The nursing homes were often described as being the residents' own home and staff themselves often felt that they were 'family' (Moss et al. 2002). Staff willingly took on the role of relative if a resident had few visitors, buying things for a resident that would normally be brought by families. Being a 'key worker' or a 'named nurse' for a resident encouraged that relationship. Caring for the same resident over a number of months and in some cases a couple of years created a bond between resident and carer in what has become known as a longitudinal relationship unique to care homes and not a known concept in hospitals and hospices (Hanson et al. 2002). Residents appreciated this close relationship. Management did not appear to recognise the degree to which staff, especially care assistants, became attached to residents and the subsequent loss when a resident died. Domestics and kitchen staff also became very attached to residents.

> *'I deliver the papers and we used to ... have quite deep conversations. When I go in now I look in the door and her eyes are open and then I go in and she shuts them.' [Domestic, NH1, FG2, pg.3]*

This same domestic had taken on the emotional and psychological caring of the residents without really seeing it as such.

> *'I thought it was just me that Ann was withdrawing with, because I have spent quite a bit of time with her in the last two or three months and now she doesn't talk. I thought it was 'me', so I had taken it personal.' [Domestic, NH1 FG2: pg.3]*

In nursing homes, all staff were exposed to 'dying' in a way that is more personal than the acute hospital setting.

> *'It's not as though I haven't worked anywhere else. I worked for 17 years in the hospital on night duty, so it is not as though I've not come across this [death/dying]. I think it is in here – it is more personal – somehow here it is closer...' [CA, NH1, FG1, pg.3]*

One nurse manager explained that just prior to starting the study, there had been three residents who had died on the same day. She had wanted to sit down with the team but the busyness within NH1 appeared to work against this. Finding time in which to support staff did not appear easy.

One striking observation was the degree of personal, unresolved grief many staff in both nursing homes carried round with them from their private lives. In just a snapshot of two nursing homes, eleven staff – eight in one nursing home – had had personal deaths they were still trying to come to terms with. One reason could be that the lower socio-economic background of care staff brings a greater incidence of illness and death. On one occasion, I had thought staff were 'withdrawing' from a resident whose death had lingered over a 2-month period. The resident's room had become unusually shabby. As I sought out one of the domestics to ask who usually cleaned the room I realised there was a very good reason. Marion told me her story:

> *'"I am finding it hard to go into Katherine's room. She reminds me of how my husband looked after he had died," she gently told me. "It's different with other residents they have died quickly; but Katherine.... well she tries to speak... and she reminds me of how it was with David". David had had a sudden heart attack when Marion was in the house with him. Marion eagerly described how it was. "I panicked dreadfully. He was sitting in the chair having a cup of tea and suddenly he grabbed at his chest and said 'Marion, Marion!' He fell forward off the chair to the floor. I had just started a 'first aid' course so I put him in the recovery position but he rolled back on to his back. He looked awful. I then tried to do mouth-to-mouth resuscitation but I couldn't do it. His chest was gurgling. I ran to the telephone and dialled 999. I was panicking dreadfully. They tried to tell me over the phone what to do and I just said 'I've done all that... He's dead, he's dead'. It took an age for the ambulance men to come. I was in the house on my own. They managed to resuscitate him but he died in hospital about a day later. There was brain damage .." David was 53 years old and had been complaining of angina while they were on holiday. She continued "He put things under his tongue but they didn't help. He had had a CXR and ECG, and was due a 24 hours tape thing the day he died". Three months after Marion's husband died her son died of a drug overdose. "I didn't fret so much over my son - he wanted to die - but Dave .... he loved life... he was always scared of dying". She told me she hadn't been sleeping well recently. "I dreamt about David last night... he felt so near.... he said 'I am here but I have to go back' so there we were getting the coffin ready and I suggested we have a party before he goes ... then my alarm went off. I dozed back to sleep but David had gone so there I was digging up the grave to try and get him back."' [Fieldnotes: 6.09.00]*

Even though the death of her husband had happened two years previously, the whole account was still very raw and she was finding it difficult to go into the room of a resident who was dying. Normally two people were 'on the floor' doing the domestic work so they normally went together. In this incident, her colleague had been sent to the kitchens to help cover sickness for a week and she herself felt unable to go into this particular resident's room on her own. The memories were so painful that she was having nightmares.

Another staff member in NH2 had problems that he had never resolved following the sudden traumatic death of his father when he was a young boy. The dreams were still as vivid. Even though the nurse manager had tried to suggest he went for counselling, he refused. Another staff nurse told me she had sought refuge in the nursing home from the stress of hospital work as a result of her father's unexpected death. I seemed to attract the stories that staff wanted to tell me quite spontaneously – it was a relief for them to talk to someone.

In NH1 with the hierarchical management it was difficult for these stories to be heard, and understood. Where hierarchical team structures exist, it is difficult for supportive and effective team working to co-exist (Wicke et al. 2004). This is not to say that no-one needs to be in charge. With a care workforce consisting of a majority of people who have little or no healthcare education facing the complex needs of frail older people in nursing homes, a nurse efficiently organising the clinical care is vital. However, efficiency isn't about power. Team working within the nursing home has to be such that staff feel valued and supported in the extremely important end-of-life care that they carry out daily in nursing homes. For a major part of the time during the study, despite the desire of a number of dedicated staff, this support, especially about end-of-life care, was lacking.

5.2.5 Relationships with the wider multidisciplinary team

Staff found professionals coming into the home to advise on care very helpful and welcomed the assistance. In NH1, a GP practice was involved with the majority of residents in the nursing home and the same GP visited once a week. The regularity of visits helped to build up a relationship of respect and trust between nurses and the GP.

> *'...I found that you actually built up a trust as it were with the medical team – so that they knew that if you phoned them and said, 'I feel that so and so is needing something more', they knew that that was the situation. So there was this trust between you.' [Nurse, FG2, pg.10]*

However, where the visits were less regular or where GPs only visited if called to see a resident, there was little opportunity for such a relationship. If a GP only had a handful of residents in any one nursing home, there was little incentive to go regularly. In interviews with GPs, the majority would have liked the regular commitment of a weekly visit to the nursing home.

> *'I think what would help to provide a better service... is allocation of a doctor to look after a nursing home.'* *[GP3 interview, pg.6]*

But the practice workload along with having to go into other nursing homes often prevented this, unless a doctor had a particular interest in the care of older people. Some GPs had patients in up to 5 different nursing homes with the subsequent difficulty of maintaining a relationship with their patients and the nursing home staff. The organising of medical services in nursing and residential homes and the impact of nursing home patients on GP practices are issues which are very much under discussion (Glendinning et al. 2002; Groom et al. 2000), although any UK-wide adaptation of services would be an enormous undertaking.

All GPs interviewed reported their reliance on a clinically based, well-experienced nurse in the nursing home. Time was precious for GPs and looking after residents in a nursing home was an added burden which some were reluctant to bear. This was highlighted on one occasion in NH2b when a GP insisted that an extremely frail resident with advanced dementia be brought to the GP practice if the nurse wanted the resident seen by the doctor. The nurse herself was unable to leave the nursing home, being the only trained staff member, so a care assistant accompanied the resident. The care assistant was powerless to prevent the subsequent ill-prepared admission of a woman with advanced dementia to a surgical ward. The distress of the resident and the ward staff, and subsequent discharge back to the nursing home the next day, highlighted the importance of a properly planned hospital admission. Some would advocate that a clinically qualified nurse at post-graduate level (care of older people) be in a position of leadership in nursing homes, in order to cope more competently with such a situation (RCP, RCN, BSG 2000).

Many nurses in nursing homes are not as experienced as the nurse manager in NH1 and require the support and teamwork of medical colleagues because of the complexity of health care needs in nursing home residents. Where a local Macmillan nurse/community nurse specialist was available to give advice, this helped and also reduced pressure on the GP's time. However, such a service is often only made available for residents with a diagnosed cancer.[43] Only 4% of nursing homes in the health board where this study took place had regular contact with such services (Hockley et al. 2004). There appears to be little relationship with these important services at present.

5.3 CLINICAL ISSUES CONCERNING DEATH AND DYING

This section focuses on clinical issues in relation to death and dying that arose mostly from the exploratory phase in the study nursing homes and were seen to challenge the development of high quality end-of-life care.

5.3.1. Closed communication in relation to death and dying

A lot of secrecy surrounded death and/or dying in both nursing homes. Even though some staff preferred to call it being discreet, nonetheless there was often an uncomfortable atmosphere, especially while a body was being removed from the nursing home. Secrecy was either encouraged by the owners of a home as the better policy, or it became accepted as the way things were done because there was no other policy for greater openness.

In NH1 residents were not informed about another resident's death unless they particularly asked. This was something that was reinforced to me on a number of occasions. It was considered that because many of the residents had varying degrees of dementia most would not notice if a resident had died and other residents would ask if they wanted to know. Residents instead found out about the death of another resident

---

[43] Fewer than 10% of residents in nursing homes have a diagnosed cancer (Sidell et al. 1997)

through other means: either through friends of people visiting the home or, as happened on a couple of occasions, through reading the announcement in the local newspaper.

Even where a nurse manager and a handful of trained nurses did feel at ease talking about dying to both residents and families, it was not enough to prevent an atmosphere of secrecy surrounding the death when a body was being removed from the home.

> *'It is the exact same thing when the undertakers come in to take the people away! You are trying to hide [residents] in rooms, you are trying to hide them in the lounge and they keep going 'what's wrong, what's wrong' and you are trying to keep them from seeing the coffin going through.' [FG3, pg.15]*

Secrecy was particularly noticeable at these times with the resulting tension among staff. My fieldnotes recount an incident following a death one Sunday morning in NH1. Unusually, the funeral directors had arrived unannounced during the Sunday service without the normal pre-warning phone call to the nurse to say they were on their way. At the end of the service those leading it were asked to keep the residents in the lounge while the body was removed. No reason had been given to the residents why they had to stay in the lounge, but they were to find out anyway as recounted in my fieldnotes:

> *'As I sat in the staff office after the undertakers had gone, I could hear a conversation between two of the people who had just led the church service and a visitor who had been 'let in' through the front door. "There's just been a death!" I could easily hear one of the couple telling the new visitor. "Oh! who's died? Was it Katherine?" "We don't know! No! It was definitely not Katherine." "Are you sure?" said the new visitor. "Yes, definitely!" There were no hushed voices but an openness of concern. Residents sitting in the lounge could easily hear the whole conversation just as I could on the opposite side of the hall [in the staff office]. Clearly a lot of people now knew without any of the staff saying anything.' [fieldnotes, NH1: 24.09.2000]*

There was an openness about this overheard conversation that I immediately found refreshing until I realised it contrasted with the 'closed' communication culture in the nursing home. I decided to wander into the lounge and met one of the care assistants preparing the tables for the next meal. She too had heard the same conversation and pragmatically continued, *"I don't know why someone didn't tell the people leading the service at the beginning. It seems to me that that would have been an ideal way of not* *only telling the residents but also to be able to pray for Sarah and her family." [fieldnotes,NH1: 24.09.2000].* This desire for greater openness was quite evident with a number of the staff.

This was not an isolated incident. Few staff had the confidence to address the removal of a body openly with residents and the time during which undertakers were in the nursing home was tense. Staff might have been trying to 'protect' residents from what they felt would cause distress; however there was always this sense of hiding residents away with no explanation and treating them like children. A further extract from my fieldnotes:

> *'13.30hrs. As I drove up to the nursing home I could see that the undertakers were outside. They were collecting Emily's body. I parked a little way off and decided to wait for a few minutes to see how this part of the routine was carried out. I waited nearly 15 minutes but nothing happened, so decided to go in. As I approached the front door, residents were milling around with a number of care assistants trying to get residents into the lounge. I thought this unusual, as normally at this time people would be being helped to the toilet and then to their rooms for a rest. I went to take off my coat and came back into the hallway. A care assistant was now by the lounge door trying to keep it shut. Another carer was asking Elizabeth to come into the lounge even though Elizabeth was insisting on going to her room. The atmosphere felt tense especially with one of the care assistants appearing to guard the lounge door. I asked what was happening "They are just about to bring Emily down in the lift. We are trying to get all residents out of the dining room first."' [Fieldnotes, NH2a: 29.01.2002]*

All focus groups provided an opportunity for a debate to occur amongst the staff as to the rights and the wrongs of this secrecy.

> *'Well it is something obviously that you keep away from other residents' [CA.NHa2, FG2, pg.3]*

> *'They don't really know most of the time...and of course you really can't discuss that with them.' [CA. NH1, FG2, pg.11]*

Still others felt that hiding death away from residents was disrespectful:

> *'Well, you'd think that when they get to the age they are they have dealt with death quite a lot at this time in their lives....people close to them and that. I don't think they are given an awful lot of credit. We are sort of treating them like children - this is how they are going to [react]. You don't know.' [N. NH2a, FG3, pg.19]*

> *'Well one of them said to me... 'you can't pull the wool over my eyes you know!'*

> *'I think they should know.'*
> *'After all, they're adults they are not wee children.' [CAs/N. NH1, FG1, pg. 13/14]*

And a sense that this hiding away was a means of protecting themselves:

> *'I think what it is that we are protecting ourselves. I just think we should have a wee bit more respect on how they feel.' [CA. NH2a, FG3, pg.19]*

Other staff hated the idea of a body being taken out of the nursing home in a body bag:

> *'We at our last nursing home.....I mean it was quite a large building with wide corridors and a lot of space, and, when somebody died instead of the undertakers coming in with the likes of a body bag or something which is horrible, we actually got them to come with a coffin and you didn't sort of ....you sort of knew some people you knew could accept being there and seeing a coffin and that the other resident would know that that person had died and seeing them go away actually in a coffin was more acceptable. We asked them how they felt about this.... and they said that 'Yes, that is what is going to happen to me style'. It was dignified.' [N. NH1, FG2, pg.16]*

When asked about the current nursing home policy and the fact that coffins weren't used, staff thought it was down to the layout of the nursing home because of narrower corridors rather than any culture of secrecy being admitted. However, I am not sure that the structure of a building creates the 'open' or 'closed' communication on death and dying.

During the exploratory phase, many residents openly talked to me about dying when learning I was from the Hospice. Forbes (2001) relates how in her study, residents were comfortable talking about death but staff had not known how to react. Those who spoke with me never appeared afraid and some even welcomed it saying, *'It would be lovely if I could go to bed tonight and not wake up!' [fieldnotes, NH2b: 13.11.2001].* In another situation, one carer was confirming to a resident that another resident had died, and the resident *'just shrugged her shoulders and carried on chatting about other things' [CA: FG1, p.13].* It appeared that management and staff were generally more afraid of death and dying than the actual residents. There was evidence that things could be done differently.

> *'Well, one day for me…when one of the ladies died…Hettie was standing at her door and the first thing she did was to bow her head [as the coffin passed] ….and that was what she did, she just stood at her door and she just bowed her head.' [CA, NH.2a, FG3, pg.16]*

The care assistant in this situation openly admitted such an incident had an impact on her and how she now viewed death and dying. There is a danger that such 'rituals', which are very useful in maintaining a more open culture on death and dying, are in danger of becoming lost.

5.3.2 Lack of psycho-social care for resident/family around dying

The closed culture around death and dying also impacted on the care being given when a resident was dying. This was not to say that physical care was omitted – both nursing homes excelled in the physical care given, which was highlighted by relatives from both nursing homes. However, there was a real danger that holistic end-of-life care was inhibited if staff could not speak about death or dying or in some cases even face a dying resident.

> *'…and you feel that it's just 'let's just get this done and get out of here' you know.' [night nurse, FG1: pg.4]*

Whether it was staff not knowing what to say to a resident if a resident brought up the subject of dying, or being afraid of actual death itself, or speaking with relatives, conversations about dying were limited. Even during handovers, euphemisms such as "she's more poorly", or "he's just for TLC", or "she's now going downhill" were used instead of openly using the word dying. A consequence of this was that on occasions care assistants didn't realise a resident was dying. Only a very few staff felt able to use the word 'dying' in the normal day-to-day context of care, even in interaction between health professionals.

Little palliative care training/education about the psycho-social aspects of death/dying had been given to staff prior to the study. Many were frightened of saying much at all in case they said the wrong thing or didn't know what they were allowed to say. Still others found it difficult to know how to behave – whether to be 'cheery or sombre' or whether residents with dementia even knew what was going on.

> *'What does the person who is dying feel about things? That is not always easy to find out. Some people are obviously easier to talk to than others or to get them talking, but I am not terribly sure when the communication is not very easy how's the best way to approach this. It is trying to 'suss out' when the time is right for them, when they want to talk about things.' [N, FG2, pg.1]*

In NH2a, where there was greater expertise in dementia care, there was acknowledgement that residents with advanced dementia did understand what was happening. Shortly after I arrived at NH2a, the nurse manager had called a meeting because a resident who had advanced dementia as well as what was thought to be an end-stage cancer and who was normally a very calm lady, was becoming increasingly anxious as her condition became weaker. The GP, a staff nurse well-known to the resident, the resident and I were there alongside the nurse manager, to try and see if it was appropriate to discuss the reason behind her feeling so unwell. The resident spoke about how her body was feeling very tired and ill; a conversation followed where we talked about dying all together including the resident. It appeared to bring relief rather than further anxiety. As the nurse manager went to see how the resident was following the meeting, she found her talking with her husband. He also had dementia and lived in the same nursing home. There she was thanking him for their life together. She died a couple of weeks later [Taken from fieldnotes 17 – 29.02.2002].

Such a scenario was an exception and probably happened because of this action research study being undertaken in the nursing home at the time. Most staff lacked confidence about their role when a resident was dying. Staff lacked the intimate knowledge of the dying process and therefore often could not accurately speak with relatives about what exactly was going on. Talking to relatives, especially when the resident is dying, is not easy. Such a skill was evident with the nurse managers and a handful of the other trained staff, but most staff tended to 'opt out'. When a lot of family members were visiting a resident who was dying, staff in both nursing homes talked about a tension that would then often pervade the nursing home. For some care staff, this increased the strain of caring for the resident. They lacked confidence as to whether or not they could go in and check on the resident, especially if the family were visiting.

> *'For instance, yesterday we got him settled at about 09.30hrs but then we thought "when do we go in again? If we don't go in again it looks as though we don't care – but we do! ... but then it is taking away from them. Because that 5 minutes that they might be out of the room he might have passed away...' [CA. FG1, pg.9]*

However, from some of the relatives interviewed, there was also little expectation of an open dialogue about dying. If this dialogue didn't happen in anticipation of a resident's death, it was not surprising that a relative might be absent.

> *'[The relatives] had been surprised that things had happened so quickly and disappointed that they hadn't been there.' [Fieldnotes: 24.09.2000]*

The 'time' factor that it takes to engage with relatives about dying was an issue and a particular frustration for some of the GPs attending the nursing home. If families of a resident who was dying were not getting answers or their needs met from the nurse in charge, then sometimes they would try to speak to the GP. But too many questions were perceived as demanding.

> *'Yes, it does take time, you know, these folks do take time. You don't always have time. So, yes! Time is an issue. What [the family] wanted to know was very reasonable but then [they] actually tried to say what they wanted, which was really beyond what was......you know...[PAUSE]....Yes, beyond what was necessary.'*
> *[GP1 interview:25.08.2000]*

Sometimes there was sadness in some care assistants. Once the family had started coming in more regularly because a resident was frailer, care assistants perceived their role had been usurped after all the caring that had gone on over the previous months/years.

> *'I find that quite hard. I think there comes the time when the family get more involved you feel it is taken away from you. You look after them all that time and you want to be there as well...you want to sit with them. It just seemed to be taken away. I felt like that with Mr A ....I thought I will go to his room and then I thought 'no I had better*

> *leave it'. You know, you just want to carry on looking after them. Yes, that's it and yet it just seems to....I don't know.....' [Care assistant, FG1: pg.3]*

Once the resident had died, then there was no follow-up care afterwards for relatives; a few relatives 'popped back' to visit staff.

5.3.3 Lack of knowledge about symptom control at the end-of-life

There was a tendency for both residents and staff to see pain as part and parcel of growing old (Frampton 2003). Regular analgesia was rarely used for the control of chronic pain. There were other occasions not only reported but also observed during the exploratory phase when care assistants would report a problem such as a resident's pain and nothing was done about it.

> *'...we know them. And if we go to somebody and say, 'she's really, really in pain and there's something not right!' and then nothing happens and [they say] 'No! it's alright – they are fine, they are fine'. And you come in the following day and that person is dead - well, the once that happened she had died. And I was so angry.'*
> *[Care assistant, FG3, pg. 24]*

If a resident did not have a specific diagnosis that warranted analgesia, it was more difficult for care assistants to persuade the nurse in charge that they were in pain.

> *'One person I find really quite challenging is Jeannie – she's not been diagnosed as having anything specific – the family don't want that but I feel that person is [in pain] and I don't feel an awful lot is being done.' [Care assistant, FG2, pg.7]*

Often a skilled care assistant who had come to know the resident's behaviour well over the months/years more accurately picked up that a resident was in pain than the nurse. Engle et al. (2001) reports that care assistants are more accurate in pain assessment because it is the care assistant and not the nurse who does the daily care. This was evident in this exploratory phase.

Similar considerations applied in relationships between the nurse and the GP. One GP willingly stated that he admired the way nurses in nursing homes had 'turned the medical model on its head' and admitted that they knew residents better so should take the lead. However, there were still times when this 'trust' did not go far enough and nurses toiled at getting what they felt was appropriate medication prescribed. Whether it was trying to get liquid medication for a resident who could no longer manage tablets or stronger analgesia or continuing the anxiolytic during the last days of life, getting the right medication was an issue.

> *'It is sometimes quite difficult to get doctors to prescribe what's needed...that can be a big problem..... They are afraid to....sort of prescribe large doses of morphine when it is needed.' [Nurse, FG3, pg.25]*
>
> *'But if somebody was in a hospice that's completely different – that would be respected right away but in here it wouldn't. It would be questioned a lot more.' [Care assistant, FG3, pg.26]*

Some nurses spoke about their concern in bothering the GP, especially in the nursing home that had several GP practices attending. On occasion, nurses had to 'persuade' a GP to take notice. In individual interviews with GPs, there was a heightened concern about the prescribing of dangerous drugs (such as morphine) in nursing homes following the Shipman trial (Mohammed et al. 2004) which was either quite explicit or more covert:

> ... *'You don't want to bump somebody off and end up in the papers.' [GP3, 13.06.2001]*

Even though there was this apprehension about prescribing of morphine by GPs, an opiate was still the most likely drug to be prescribed in the last days of life just because the person was dying.

Trained nurses and nurse managers within a nursing home have an important role not only in co-ordinating end-of-life care but also in reporting and advising on symptoms in the last days. If the staff knowledge of end-of-life drugs is inadequate then there is a danger of suffering. There was little distinction between pain and agitation in the last days reported in the focus groups. However, there were some particularly horrifying descriptions. One story stood out in the minds of those in NH2 concerning a resident who had extreme pain from wet gangrene, not an uncommon occurrence in the nursing homes. The death had occurred six months previously but staff remembered it as though it had occurred yesterday:

> *CA4* *'Her pain relief was not even touching her.*
> *CA2* *She was in absolute agony. She had a complete black leg up to here...*
> *CA3* *I am sorry I couldn't even watch it.*
> *CA2* *...and her pain must have been unbelievable. Dying from the outside inward..*
> *N5* *She was flinching every time...*
> *CA4* *She was bent over in pain*
> *CA2* *I don't think her pain was always just in her leg. It must have been going elsewhere*
> *CA4* *The pain was terrible that that woman went through....*
> *CA2* *She was in absolute agony.'* *[FG 3, pg.22 – 11.04.2001]*

There was a huge sense of relief from the staff when this lady eventually died. Although pain was an issue, especially for residents with muscular-skeletal problems who were up and about, observing severe pain in dying residents as described above was uncommon.

The observation of end-of-life care revealed a greater problem with agitation than with pain. In the study nursing homes, anxiolytics were not considered an important drug in the last days of life. Instead both staff and doctors would consider morphine if there was agitation – yet such a drug could make the situation worse. At the beginning of the study, anxiolytics were rarely thought necessary to continue into the dying phase, even though a resident might have been on such a drug for many years.

> *'I went in to see AB. He was lying on his side in bed facing the door. His head was retracted back. He was clearly conscious, as his eyes were wide open. I touched his 'scrunched up' fingers and there was a response from him. His breathing was not chesty in fact I thought his chest was quite clear .... I asked [the nurse manager] what effect it would have on the patient if Parkinson's drugs weren't given "Oh awful!" she said. "So his retracted head is likely to be made worse because of all this?" "But at least he's maintaining his airway" was her serious response.... In my opinion this gentleman was in dire need of an anxiolytic. The Cyclomorph injections appeared to be making things worse.' [Fieldnotes: 09.11.2000]*

This situation was resolved with a conversation between the nurse manager, the GP and myself. An anxiolytic was prescribed and the gentleman settled and died very peacefully with his family present within a 24-hour period. There are similar situations where terminal agitation is a common symptom as a result of a disease such as dementia (Hall et al. 2002). There was a lack of understanding that long term drugs needed to be continued into the dying phase. The lack of knowledge on the part of both GPs and nurses in the nursing homes about medication other than an opiate to control symptoms in the dying phase was considerable. When a resident had not been on any medication prior to the dying phase, however, then there was the chance of a very peaceful death, with little to no medication required.

5.3.4 End-of-life decision-making and anticipation of the dying phase

'Bounce back' was a phrase often used by staff to describe the 'recovery' of a frail elderly resident in the nursing homes. Such a phenomenon is seen as part of the dwindling dying trajectory of very old people (Lynn & Adamson 2003) and was regularly referred to at 'handovers'. Because of this 'bounce back', it was sometimes more difficult to accurately recognise dying in this population.

There were different causes for this 'bounce back' phenomenon. One obvious cause was the lack of careful monitoring of regular diuretics. The over-use of a diuretic in a resident who was not taking adequate fluids precipitated dehydration, which in turn precipitated sleepiness. The resident would then miss a couple of days' diuretic tablets, be encouraged to take extra fluids and 'bounce back' would occur. Another cause of 'bounce back' was less passive, and was due to the repeated use of antibiotics for chest infections at the end-of-life. Pneumonia was rarely seen as the 'old man's friend'. Although a few nurses were concerned about the use of antibiotics in end-of-life care, the majority went along with what was suggested by the doctor. When GPs were called to see a resident because of deterioration, treatment was often given without reference to the resident's overall quality of life. Many nurses felt uncomfortable taking responsibility for making the decision that a resident might be dying even if the GP attending was a locum. More often than not, nurses saw a decision around dying to be the responsibility of a doctor rather than a joint decision in which they play an active part.

Where there was a weekly medical presence, as in NH1, the necessary trust and mutual respect eased difficult end-of-life decision-making. In such situations, the nurse was prepared to speak up and address the unsuitability of a further antibiotic or an admission to hospital with a GP, and as a result a more appropriate decision was made. The professional relationship between the GP and nurses in NH1 often prevented unnecessary prolongation of life (Singer et al. 1999).

Some residents were very matter-of-fact about what care they wanted at the end-of-life. During a focus group with residents in NH2a, a lady was quite adamant she saw a resident's recent sudden death from a heart attack as a 'very lucky way out'.

> *'And I would not like to be kept here if I had a similar heart attack. I would not like to be resuscitated. I feel as though I have had a good innings.... I mean, I am now 87 – so I think that is a very good age.' [Resident Focus Group, pg.11]*

If staff knew a resident's wish because of a living will, staff felt more comfortable about end-of-life decision-making. In NH2, four residents had a living will. Singer et al. (1999) report 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.

Even when a decision had been made that a resident was dying, there was little anticipation of what care and what drugs might be necessary during the dying period. Much anxiety, and wasted time, could have been avoided if more attention had been given to the anticipation of appropriate drugs for end-of-life care.

> *'I just presumed it was in our cupboard. But there was nothing there so I had to phone the doctor out. It was unfair on the doctor as well.' [Ns. FG1, pg.16]*

There were numerous issues to do with getting the medication. Often care assistants were asked to leave caring for a resident to collect an unexpected prescription from the chemist. On some occasions I offered to go because the nursing home was busy. There was also little anticipation of a dying resident's need for subcutaneous medication. So this haphazard nature of getting medication, especially at night or at the weekend, added to the stress.

> *'Mr White was given Cyclomorph at one o'clock [lunchtime].. You knew...the chances were he was going to need some more. And there was none available although the family were told that if he needed any more Cyclomorph the staff nurse would get it for him. And that's where I came into difficulties. I had to call the doctor out ...the doctor didn't know him...she was obviously concerned because she really didn't know how to deal with the situation. She suggested a syringe driver and I didn't know where to get a syringe driver from.' [Night nurse – FG1, pg.15]*

The frustration of trying to get a prescription for a dangerous drug for someone who was dying added to the stress of balancing the care to other residents. Because nursing homes are 'in the community', they follow drug procedures as for someone dying in their own home; palliative care drugs are not kept as 'stock' as would normally happen in a hospital. However, if drugs were prescribed in anticipation and then not used and subsequently destroyed this was seen as a waste of money. GPs were willing to 'come out' and prescribe necessary drugs at the end-of-life, but this defeated the purpose of anticipating symptoms at the end-of-life and preparation being made. The doctors who often ended up being asked to visit were 'out of hours' doctors who thus did not know the resident.

The unnecessary stress this caused while waiting for doctors to arrive and collecting the necessary drugs especially at night and weekends was considerable. Staff in both nursing homes felt things could be better.

> *'We need better and clearer guidelines.' [N. FG1, pg.15]*
>
> *'I am very aware of forward planning rather than waiting until the event is upon us. Especially in respect of analgesia and other symptom controlling agents. To try and avoid 'crisis management' of symptoms near to death and avoid distress to resident and family' [N interview, NH2a]'*

Because of the difficulty of diagnosing dying, there was a tendency therefore for residents to be dying before it was recognised. This often meant that dying, for a lot of residents in the nursing home, was quite independent of any real recognition of the importance of such a significant event.

5.4 REFLEXIVE DISCUSSION

At the end of this chapter and in the following two 'analysis' chapters, space is given to discussion on issues relating to the doing of action research as well as to specific themes on end-of-life care emerging as a result of the study. As previously mentioned, Meyer (2000), when referring to Carr & Kemmis (1986), highlights the importance of three aspects of action research – its participatory nature, its democratic impulse, and its ability to bring about social change at the same time as adding to social theory. Participation in the action research process and coming to a decision about what actions should be taken forward is now discussed alongside a major theme: the 'peripheral-ness' of death and dying within the nursing home context – a theme which is highlighted now but one that becomes increasingly relevant as the thesis progresses.

5.4.1 The 'peripheral' focus of death and dying in nursing homes

The longer I was in NH1 and NH2, the more I became aware that the closed communication culture towards death and dying was pushing dying to the periphery of nursing home care. Increasingly I realised that a resident who was dying was often quite 'alone'. It was a specific incident in NH1 that made me increasingly aware of how 'peripheral' death and dying was within the overall focus of care in both nursing homes. Reflecting on this specific incident was to illuminate this concept, which was then confirmed with other episodes during the study.

The incident occurred on 'bonfire' night when the owners of NH1 had invited relatives and friends of the residents to a superb meal and a firework display. The invitation was extended to me and I willingly accepted. During the evening the dedication of the owners to giving residents/families and friends a good time was very evident. They and the nurse manager worked extremely hard. The following is from fieldnotes:

> *'As the fireworks began I was suddenly conscious of the enormous noise coming from the garden which was in close proximity to the room of a resident who was known to be dying. I slipped out and went down to her room to see if the resident was alarmed in any way by the fireworks. As I knocked and entered the room the curtains were closed but reflections from the fireworks played across the ceiling. I went across to Catherine whose face was turned away from the door. As I sat down an enormous firework exploded and Catherine's eyes opened in a startled stare. I sat and held her hand explaining it was 'firework night'. I was unsure whether the explanation was absorbed but my presence appeared to calm her….' [Fieldnotes: 4.11.2000]*

I would not necessarily expect the owners to think about this resident as she lay dying. The owners of NH1 were very involved in their nursing home but had no professional health background. However, it was one of those situations that started a train of thought regarding the degree of isolation that dying residents might experience in nursing homes. In contrast to the bed of a dying patient being brought to the top of the old 'nightingale' wards near the sister's desk, in the study nursing homes people were very much on their own in their rooms.

The owners of NH1 were very committed to the home and wanted to put on 'extra things' for the residents and their families. However, this 'rehabilitative' culture often meant that dying appeared to be on the periphery of the care culture. A fear and to some extent ignorance about death and dying was prominent in the management of this nursing home:

> *'…because you know yourself you are going to die sometime but if you had a grasp of how it was going to be and when it was going to be you would go and cut your wrists now… rather than wait for it coming to you….' [NH1. NH owner interview: pg.8]*

Such a fear about death and dying clearly influenced how end-of-life care was managed at a clinical level. Despite many care assistants in NH1 having a natural aptitude towards coping with death and dying, this naturalness appeared stunted by the fear of what they perceived they were/were not allowed to say and do. Management's need to protect themselves, and therefore staff and other residents from death, appeared to undermine the importance of dying.

Such a scenario did contrast with the occasional conversation or comment from staff who spoke about how they were used to dealing with death and dying 'differently'. This was either before to the current management or how it was done differently in other nursing homes where staff had worked previously.

> *'...I suppose me coming from where I came from before which, I am not saying was better, it was just different. It was much further down the line if you like in terms with dealing with death and dying.' [Nurse manager interview, NHa2: pg21]*

Brazil et al. (2004) highlight six themes in their focus group discussion with staff about end-of-life care in sixteen long-term care facilities in Canada. One of the themes highlighted is the importance of recognising death as a significant event. There is a tension created between the rehabilitative culture (Leyland 2000) of nursing homes and keeping residents 'cheery', and recognising the significance of a resident's last few days of life. Without this recognition, the importance of such a significant event is lost, not only for the resident but also for other residents in the nursing home, and the staff.

When death is recognised appropriately in nursing homes, it helps to affirm the naturalness of dying at the end-of-life (McCue 1995). Cox & Cook (2002) report one example when a resident, who had decided herself not to have further antibiotics for pneumonia, was brought in her bed to the lounge where she had her favourite view of the sea. A nurse would sit quietly at her side and at the same time keep a watchful eye on other residents in the lounge. Despite being in the last few days of life, this resident remained at the centre of nursing home activity. And, as McCue (1995) states so eloquently, 'respect for the wholeness of life requires that we not debase its final stage' (p.1039).

In NH2a, things were slightly different. The nurse manager saw the importance of being able to discuss a resident's wishes about death as part of the admission procedure rather than have it left for discussion when the resident was actually dying.

> *'..and make it part of the admission procedure, because then it's not something that's disembodied and made to be different... So we asked people, you know – had they*

> *thought about it? Did they have any preference about being cremated or buried? – and we pointed out things like ... we want to do things that you would like done, and the wishes of the family... we would try to make the comments as normal, if you like, with the admission... I think that's what we should do here. And we don't... because it is not something that's been there.' [NH2a. Nurse manager interview: pg.8]*

This openness was affirmed by residents during a focus group that the nurse manager in NH2a helped to undertake as part of the study. She had wanted to clarify with residents how *they* wanted staff to communicate about death and dying in the home. Despite this eagerness, staff themselves found it difficult to translate such an approach into practice. Komaromy et al. (2000) stress that the

> *'experience and qualification of the head of home, including his/her understanding of what constituted a well-managed death, therefore influenced the way in which death and dying was managed.' (p.194)*

I believe this is true to a degree but staff need training and support to ensure that it is carried out in practice. The leadership in the different nursing homes had different approaches towards dying; one a 'less open' approach, while the other openly promoted the importance of end-of-life care. However, despite the different approaches in management, there was still a peripheral-ness of death and dying in *both* nursing homes. As I reflected on this, I sensed that the peripheral-ness of death and dying was as much about clinical confidence in recognising and taking responsibility for residents who were dying, as it was about the organisation or culture of care. This complex mixture of issues, with differing proportions of all three within the different nursing homes, was something that would require the participation of both staff and management in agreeing to take appropriate action/s forward.

5.4.2 Staff participation in the action research process

One of the three key elements of action research highlighted by Meyer (2000) is *participation* between researcher and practitioners. In this section I discuss my reflections on participation in relation to how the exploratory phase and the facilitating action phase were conducted.

The feedback of the exploratory phase in both nursing homes was done both formally (see Appendix 7) and informally via group discussion which all members of staff were encouraged to attend in order to have their voice heard as to how things could be taken forward. One could argue that staff participation in the exploratory phase, especially in NH1, had been quite passive. They had been involved in focus groups and interviews but were in many ways, as I now realise, not taking the initiative as co-researchers as much as I believe they could have.

As I reflect on the level of participation in the exploratory phase in NH1, I realise that there were specifically a couple of reasons why there was less participation than there could have been. Firstly, I had never been involved in an action research methodology before. In reading much of the literature, I had over simplified the 'observe, plan, act, and reflect cycle' (Stringer 1996; Kemmis & McTaggart 1988) of my early reading and had not realised the importance of participation alongside all aspects of this cycle. Secondly, there was a pressure that I felt to be performing as a researcher in front of the owners and nurse manager of NH1. Much of this could have been self-generated because of a degree of insecurity in what was an unpredictable methodology. But there was an obvious scrutiny of 'what I was up to'. *I* could have been more participative with the nurse manager in NH1. However, the pressure on her 'time', much of which was taken up with her commitment to excellent physical care and reporting on a daily basis to the owners, meant time for the action research study was eroded. There was an expectation that the research was *my* business and at this point in the inquiry I was content with this. However, what was clear was how staff would take responsibility for fashioning the most appropriate way to *plan* the development of end-of-life care in their home at the feedback of the exploratory phase. In contrast in NH2 the nurse manager had been more involved in the actual research process of the exploratory phase. She had helped lead the focus group with residents and had been involved with individual residents in obtaining their informed consent.

The informal feedback, carried out through two discussion groups in NH1 and NH2, went very well, with the majority of staff attending. However the more formal feedback of the written report provoked a stronger reaction, especially from the owners and nurse manager of NH1. On looking back I am not sure why I wrote a formal feedback, other than there being a certain expectation that this was what was required. Perhaps it was to clarify things in my own mind in order to express it more coherently to nursing home staff.

I now see how the 'hard' evidence of written feedback was likely to alarm nursing home owners who were governed by a 'regulatory' system of approval. It was as though the feedback had slighted the hard work of the NH1 owners and the nurse manager, even though the feedback highlighted the excellent physical care of residents and the keenness of many staff for quality end-of-life care, with suggestions for discussion on development of practice. Reporting back about the end-of-life care issues was not a problem, as there was an expectation that that was why I was there. However, aligning some of the end of-life care issues with organisational issues such as staff support, management and the importance of a learning culture in the written feedback was not welcomed and caused an initial difficulty in the relationship between the owners and myself. As a result, my 'outsider' position in the action research process was highlighted. As an 'outsider' I was told it was not for me to comment on how care was managed in the home even though it influenced end-of-life care.

Titchen & Binnie (1993b: 859) report 'tension between the researcher and the actors in the 'outsider' model'. However, there were advantages of being an 'outsider'. I was able to be naïve about the culture. This enabled me to understand the important differences (see Chapter 7) between the nursing home context and that of the hospice.

Meyer (2000) highlights the importance of trust when 'outsiders' work with practitioners within an organisation. From the beginning it appeared that trust had developed very easily with the staff 'on the floor'. Even with the nurse manager and owners of NH1, there did not appear to be a lack of trust while talking about issues within the nursing home, even when it was about managerial aspects of care plans and staffing. It appeared that some trust was lost when I presented the formal feedback. Feeding back the results appeared a crucial point in the action cycle where 'trust' is most easily threatened. Setting up this 'trust' earlier in the study and highlighting possible difficulties and conflicts as a result of undertaking an action research study was to be a learning point for me when I moved to NH2. The setting of clear boundaries at the commencement of any action research study helps to create trust within the ensuing dialogue (Meyer 2000).

Meyer's emphasis on 'trust' brings the whole concept of insider/outsider to a more relational level and this was something I had worked hard at trying to achieve. The actual report in NH1 was not changed to any considerable degree before the owners and nurse manager were content for it to be circulated to the rest of the staff. Trust appeared to be retained through dialogue, but their reaction to the report should have forewarned me of possible difficulties ahead in relation to embracing change.

Whether it was because I had learnt from my experience in NH1 about the need for greater regular dialogue with management, or that those I was working with in NH2 were more open to change and less threatened by the report, or that I was more removed from 'top' management was difficult to say. However, it was noticeable through leaflets on notice boards and from how the nurse manager approached the study that the management at NH2a valued the importance of change and were particularly interested in developing end-of-life care. The written report therefore was seen as being constructive. It had been a particular strategy when looking to appoint a second nursing home in the study to find one where there was not only a nurse manager versed in a more patient-focused care model but also where the challenge of change would be willingly grasped.

NH1 being a small nursing home where the owners were present every weekday, it was understandable that they wanted to be involved in guiding the way in which things were taken forward. One of the owners was present at the informal feedback discussion. We talked at length altogether about what angle to take – symptom control, more 'open' communication about death and dying, care plans, support for staff, reflecting on deaths that different staff were involved with, etc. Although the staff had made it very clear during the focus groups that they wanted to work on a greater openness in communicating about death and dying, the owner was not keen. I tried to quieten any alarm over greater openness with the fact that I would be around as a nurse specialist to help. However, the owners were concerned about the untrained care assistants and the liability in case communication of death and dying got 'out of hand'. As we discussed altogether, I mentioned learning about end-of-life care through reflecting on care given following the death of a resident. Could such a session perhaps also help to support staff, especially care assistants, alongside learning from within practice? This received considerable interest from both care assistants and trained nurses, but also considerable enthusiasm from one of the owners. It was agreed that the reflection session would include aspects of symptom control as well as support, communication and the psycho-social aspects of care. The person who was most apprehensive about this way of learning was the nurse manager.

In NH2a the same procedure was followed. It was a bigger nursing home and felt much busier than NH1. This could have been because there were considerably more residents who were debilitated with quite severe dementia alongside a lower staff-to-resident ratio. Staff were eager for me to do tutorials on various subjects as well as reflecting on a death. There was money from the education budget that would pay for staff to attend not only the group work after a resident had died but also the tutorials. However, the tutorials were never really that well attended. There was considerable work pressure on staff during the shift and most staff felt exhausted. So it was decided by them that they would in the first instance like to start with the reflection sessions and then reassess.

5.5 CONCLUSION

This chapter has described the context within which the actions for developing practice and knowledge of end-of-life care in both of the nursing homes were to take place. Although there were differing leadership styles to do with organising the nursing care during the time of the study, the development issues around the end-of-life care needs of older people were in fact not dissimilar in the nursing homes. The specific issues that both staff and I agreed to address were: the need for staff to feel adequately supported when a resident was dying, aspects of symptom control, learning through reflecting on the practice of end-of-life care, and encouraging a greater openness about death and dying in order to bring it more into focus of nursing home care. The next chapter (Chapter 6) describes how through the setting up of 'collaborative learning groups' following a resident's death these groups became an opportunity for facilitating change in end-of-life care within the context of both nursing homes.

CHAPTER 6:

FACILITATING CHANGE THROUGH 'COLLABORATIVE LEARNING GROUPS'

Issues that prevented quality end-of-life care in the study nursing homes have been highlighted (see Chapter 5). Because of some of these issues, dying appeared peripheral to the focus of nursing home care. This present chapter details the way in which nursing home staff chose to develop their knowledge about end-of-life care through group reflection.

Following the previous discussion on reflection as a way of learning (see Chapter 4), this chapter looks at experience-based learning for staff as a way of improving knowledge about end-of-life care. Sessions called 'collaborative learning groups' (CLGs) were arranged following a resident's death in the nursing home. Analysis of data from ten taped CLG sessions undertaken in both nursing homes showed differing ways that knowledge about quality end-of-life care was gained. A staff evaluation questionnaire revealed that these groups not only fulfilled a learning function but also helped staff to feel supported and valued for the work that they did. Because of the lack of continuity in staffing, the CLGs also gave staff opportunity to communicate with each other. The chapter concludes with a reflexive discussion about the continuing organisational difficulties of developing knowledge about end-of-life care specific to the context of both nursing homes and how this in turn influenced a further action cycle.

6.1 FINDING A FRAMEWORK FOR THE 'COLLABORATIVE LEARNING GROUPS'

In response to the 'feedback' discussion of the exploratory phase in NH1, one of the nursing home owners unexpectedly encouraged a suggestion posed by myself that we use reflection on practice as a way of enhancing staff knowledge of palliative/end-of-life care. The majority of staff were also very enthusiastic about having an organised time to reflect together on practice. However, the nurse manager in NH1 was not so comfortable and was sceptical about this way of learning. She had had little opportunity to hear about reflective practice because of the relative isolation of the private care sector from NHS education (Katz & Peace 2003). However, because of her respect for the owners with whom she had worked for seventeen years, she was willing to see what might develop.

As a result of much discussion in the home, I began to search the literature for an appropriate framework to incorporate a way of helping both trained nurses and care assistants reflect together. Davies (1995) suggests that reflective practice can enhance a number of practitioner skills, including self-awareness and confidence. Being aware of feelings through reflecting on situations can help practitioners understand better why a certain action had been taken and what might have been a more appropriate alternative. Most theorists (Johns 1998; Gibbs 1988; Mezirow 1991) on reflective practice encourage the keeping of a reflective diary and the use of a model to structure the experience of reflection as an individual. The trained nurses in the study nursing homes had already been encouraged to keep a reflective diary, and a training session about reflection had been given. However, a framework for *group* reflection, with the emphasis on learning from experience where the majority of staff were untrained, was not so obviously available.

Group de-briefing has historically been set within the battle context where soldiers are brought together to describe what has happened in combat and to hear further 'briefing' instructions (Pearson & Smith 1985). Research looking at the effect of group de-briefing of Israeli soldiers exposed to combat (Shalev et al. 1998) and British soldiers returning from peacekeeping operations in Bosnia (Deahl et al. 2001) reveals better group cohesiveness and reduced anxiety as a result of the group de-brief. Within nurse education, clinical debriefing has been found to reduce anxiety in first-year student nurses (Davies 1995).

Besides the above research showing group debriefing as reducing anxiety, Pearson & Smith (1985) discuss 'de-briefing' within a context of learning. In nursing practice, much learning takes place through experience even though sometimes this might not be realised. Pearson & Smith (1985) put forward an argument for experience-based learning where learning is realised through group reflection. They go on to suggest that there are three different ways in which people learn in groups depending on how such a group is led – 'being taught' within a group; being helped to understand personal and cultural beliefs about practice; and being empowered to bring about appropriate change in practice by the promotion of critical knowing by which attitudes are challenged. The latter approach to learning advocates: 'sharing power, authority and responsibility for learning, and working towards collaborative learning in debriefing' (Pearson & Smith 1985: 78). This was something I felt was important to build into the collaborative learning groups (CLGs) we were hoping to establish.

One other consideration for running a reflective group was to use action learning (McGill & Beaty 1995). Action learning sets are necessarily composed of the same and relatively small number of people at each group or 'set' (McGill & Beaty 1995). They have a strong emphasis on critical learning and encourage participants to think through how they can bring about change. In NH1, there was a large majority of staff very enthusiastic to be involved directly, and choosing action learning would inevitably exclude some people because of the small size required of the set. However, it was also unlikely that the same staff would be able to attend regularly because of pressure on time, staffing and the 'off duty' rota. There was the added concern as to whether it was appropriate for the CLGs to have just the 'critical' format to knowledge generation; the evidence from the exploratory phase revealed that there was considerable lack of knowledge about palliative care and some staff might need to be taught more directly. With the nurse manager in NH1 rather tentative about the value of reflection, I felt a more inclusive format for knowledge generation rather than an elite group of an action learning set, where she might not choose to take part, was more appropriate. The de-briefing format proposed by Pearson & Smith (1985) was therefore adopted.

Because of my own clinical experience and knowledge of palliative care, my hope was that this would ease the discussion of any subject to do with death and dying in the CLGs. I wanted the groups to challenge current thinking about end-of-life care in the nursing home, including challenging me about any inappropriate theory that I might be bringing from specialist palliative care. Staff knew I was from the hospice but I wanted them to realise how much experience they had in advanced dementia. I wanted to be able to show the importance of learning *with* them about end-of-life care in the very old. My aims of setting up collaborative learning groups in the nursing home were threefold:

- to uncover and encourage experience-based learning within the nursing home setting
- to support nursing home staff in the care of dying residents
- to construct knowledge about end-of-life care of the very old in nursing homes

6.2 COLLABORATIVE LEARNING GROUPS (CLGs)

Pearson & Smith (1985) advocate a minimum of 40 minutes for an experienced-based learning session, and longer where a group reflection is involved. In the nursing homes, however, there was considerable pressure to keep the CLG sessions strictly to a maximum of 45 minutes. This made it difficult on some occasions to bring a session to a close. Often a session could have continued well over an hour, and very occasionally in NH2a this did happen. However, it would have been extremely difficult to negotiate this length of time at the beginning because of staffing and time constraints.

In both NH1 and NH2a, the group sessions were held between five and ten days following the death of the resident. The group met following the commencement of the afternoon shift and consisted of staff from both shifts with those from the morning staying on in order to attend. The CLGs followed a certain format (see Box 6.1). This gave the group a degree of structure but also allowed flexibility for staff to participate within the CLGs as they felt able.

Box 6.1: Stages in CLG session
(Adapted from Pearson & Smith 1985: p.72)

1. Brief résumé of resident/family whose death was being discussed.
2. What happened?
    - Description of own and other peoples' actions/involvement
    - Different times, shifts, experiences
3. How did the participants feel?
    - Exploration of personal + interpersonal feelings
    - Anticipation of unexpected expressions of emotion
    - What was 'good' ...what was 'bad'?
4. What does it mean?
    - What can we learn ... how does practice need changing?

At the beginning of each session, one of the staff present gave a brief résumé of the resident's life, their time in the nursing home and their family. Group members were invited to 'tell what happened' on the different shifts during the last few days of the resident's life. We discussed what had been 'good' about the care and what we might have done better. Participants were encouraged to refer to what they had written in their reflective diaries if they had completed them, or to explore some of the 'raw' feelings that they had been conscious of during the resident's dying phase. Finally, we discussed what we could learn from the situation and what we would do differently next time. The sessions mostly ended with staff recounting what they had learnt but on some occasions the timing of the session had overrun and this got cut short.

Twenty-four CLG sessions were undertaken in NH1 and NH2 altogether; ten of these were recorded and transcribed. Thirty-four different staff members attended one or more of these ten sessions. Including myself, there were never fewer than four people at a session and groups generally consisted of six or seven people. Different topics on end-of-life care were covered (see Table 6.2).

There had been no original intention for the CLGs to be tape-recorded. I had wanted the least threatening atmosphere possible in the sessions in order for people to feel safe enough to share whatever they liked about the situation under discussion. However, after a number of CLGs had been held in NH1. a night nurse was very disappointed not to be able to attend a particular planned session. A suggestion of taping the session was made by me so that she could listen to what was discussed in her absence. As a result of this request, I realised that taping all subsequent sessions might provide data that could evidence the facilitating of experienced-based learning in end-of-life care within nursing homes. I asked group participants if I could tape subsequent sessions so that they had the opportunity to listen to a session if they were not present and I could use the data for my thesis – all willingly consented. Not having taped earlier sessions had encouraged an ease of communication that continued into the sessions that were then to be taped. Only 4/10 taped CLG sessions occurred in NH1 before I moved to NH2. A further six sessions were taped in NH2 before a major change in staffing following the departure of the nurse manager.

Table 6.2: Collaborative Learning Groups

CLG	Nursing Home	Age of resident + time in NH	Topics discussed	Staff present at Rd-BS
No 1	NH1	97yrs [3yrs 5mths]	Dwindling trajectory; dying process; family involvement re end-of-life decision-making; incontinence at E of L; 'natural' dying; no need of E of L medication; speaking with family but still closed communication with other residents; increasing dependency of residents.	**6** (matron, N x 1, C/A x 4)
No 2	NH1	88yrs [2 weeks]	Respite admission & sudden death; guilt; need of staff support; recognising dying; dying process; taking responsibility; learning through 'reflection'; breaking bad news over phone; honesty; using the word 'dying/died'; sitting with the dying.	**5** (Matron, N x 2, C/A x 2)
No 3	NH1	78yrs [3 weeks]	Gangrenous pain; complex pain control; importance of having medical background on resident; rehabilitative v. palliative care culture; evidence of increasing knowledge of strong opioid use; continuity of care; importance of m/disciplinary team in E of L care.	**4** (Matron, N x 2, C/A x 1)
No 4	NH1	81yrs [1yr 11mths]	Dying process; premonition of death; resident dignity/choice; learning how to use 'out of hours' pharmacy for E of L drugs; importance of a clinical expert as nurse manager; taking responsibility - communication with family; sitting with a dying resident; highlighting the importance of 'dying'; appropriate use of opiates at E of L; dehydration & dying;	**3** (Matron, N x 2)
No 5	NH2a	88yrs [1yr 9mths]	Dwindling trajectory; anticipating dying; dying process; taking responsibility; communicating about dying; supporting young care assistants (CAs); marking the dying process; antibiotics at E of L & end-of-life decision-making; natural dying; constipation & dying; dehydration & dying; GP continuity; pain v. agitation when dying and use of anxiolytics.	**6** (Matron, Sr, N x 2, C/A x 2)
No 6	NH2a	93yrs [1yr 10mths]	Speaking to relatives; seeing resident & family as unit of care; dying & constipation; pain assessment / management; sitting with the dying; fear of new things - drugs to control symptoms at E of L; going to funerals; pharmacists getting E of L drugs.	**6** (Sr, N, C/A x 3, domestic)
No 7	NH2a	98yrs [1yr 11mths]	'Unexpected' but timely deaths; premonition of death; death as celebration; natural dying; support of staff; working as a team; CAs fear of death in NH; person-centred care; residents as 'family'; telling other residents about a death.	**6** (N x 2, C/A x 4)
No 8	NH2a	81yrs [2yrs]	Terminal restlessness; end-of-life decision-making & family; pneumonia as 'old man's friend'; quality of life; Fentanyl patches; dehydration & dying; importance of staff communication; speaking about dying with resident despite dementia; coordinating removal of body; open communication - telling other residents; saying 'good-bye'.	**6** (Matron, N, C/A x 3, activity coordinator)
No 9	NH2a	87yrs [7mths]	Sudden death; shock/guilt; support of CAs +; isolation of some residents – 'those who do for themselves are left to themselves'; breaking bad news of sudden death;	**7** (Sr x 1, N x 2, C/A x 4)
No 10	NH2a	86yrs [1yr 9mths]	Sudden death; resuscitation; support; honesty when breaking bad news; taking responsibility; guilt over being immune to 'buzzers'; rehabilitative v. palliative care culture; involving families in communication over end-of-life decision-making; pain.	**7** (Sr x 1, N x 2, C/A x 4)

With the arrival of the new nurse manager in NH2b, the focus of the action phase changed (see Chapter 7); because of this, the taping of subsequent CLG sessions did not continue.

6.3 MAKING SENSE OF THE DATA

Each of the ten 'taped' CLGs was transcribed following the session. Initial coding was performed at this time using a data form sheets (Mile & Huberman, 1994) displaying the page number of the salient point/text alongside the code (see Appendix 6). However, following the analysis of data from the summative evaluation questionnaire when I left NH1 and NH2a, the qualitative comments regarding the CLGs fell into three main categories: education, support and communication. The data form sheets and the transcribed texts from each CLG were then re-examined for content relating to these categories. The initial coding was then collapsed under these three categories. These three categories became core outcomes of the CLGs (see Table 6.3).

Table 6.3: Core Outcomes of Collaborative Learning Groups

CORE OUTCOMES of the collaborative learning groups	
1. EDUCATIVE: experience-based learning	i) Individual learning and gaining knowledge – *"being taught"* ii) Mutual understanding of end-of-life care – *"developing understanding that influences practice"* iii) Critical knowing & adding to a theory of end-of-life care - *"challenging the status quo"*
2. SUPPORTIVE	Opportunity to share together some of the difficulties surrounding death & dying
3. COMMUNICATIVE	Aiding communication across the nursing home among the different personnel involved in the care of the very old at the end-of-life.

The evidence for the core outcomes of the CLGs is examined in detail in the next two sections. The educative role is discussed in Section 6.4; the supportive and communicative roles are discussed together in Section 6.5.

6.4 EDUCATIVE ROLE OF CLGs

There was evidence within the transcripts that the CLGs provided a basis for experience-based learning following a resident's death in the nursing home. In what manner staff gained this knowledge was examined. As a result of Pearson & Smith's (1985) work, I was interested to know whether my facilitation of the group encouraged any one way of learning or whether it was possible for different ways of learning to occur. The transcripts revealed clear elements of 'being taught' and individual learning about aspects of end-of-life care on subjects that were completely unknown to staff, especially care assistants, who had little technical knowledge about death and dying. However, there was also evidence of nurses' and carers' values and beliefs relating to end-of-life care being individually explored through the various sessions. Many staff were experiencing greater mutual understanding through reflecting together on their experience of caring for the resident whose death was being examined. There were also times during the CLGs where staff felt able to challenge the status quo and were more willing to take responsibility in engaging with dying residents and their families; people were being challenged to change their own practice. This resulted in highlighting specifics about the dying process of older people in the nursing home context.

6.4.1 Individual learning and gaining of knowledge by 'being taught'

During the CLGs, differing group members took the opportunity to share their knowledge about certain aspects of palliative care. More often than not, this would be either the nurse manager of the home, one of the trained nurses or myself taking the opportunity to pick up on an issue being discussed and directly teach about it. Because teaching was done in this way, specifically relating to the care given to a person that staff had known, care assistants especially were able to identify real live situations upon which they could base their learning. In both nursing homes, there was evidence of issues 'being taught' about the importance of holistic end-of-life care for residents and their families. The groups were dynamic; what issues were raised in the groups depended not only on specific issues to do with the death that had occurred but also on the staff present and what issues they themselves wanted to raise. Different topics were raised in the CLGs (see Table 6.2).

One of the topics frequently raised was about dying itself; staff wanted to know the mechanism by which frail older people came to die. McCue (1995) highlights the importance of seeing dying in old age as an inevitable process that is independent of underlying disease(s). Some staff, especially care assistants, needed to understand dying in the very old as a gradual dwindling trajectory (Lynn & Adamson 2003), occurring over many months rather than a sudden event; one that could be predicted if one was alert to it. Many staff did not realise the importance of pneumonia as 'the old man's friend' being integral to this process.

> *'... it is really important that we are able to talk together as a team... em... with the nurse manager and the doctors, just to know what we think .... Of the situation. How much we prolong things [with antibiotics] and how much we allow nature to take its course. Because pneumonia has been well documented as the 'old man's friend'."*
>
> *"Oh, right! I didn't know that!'* *[JH & CA. CLG.7]*

Through formally describing actual deaths in the CLGs, the process of dying was now being regularly explored in a more 'open' way. Staff were learning from each other as they told their stories or talked about their concerns.

> *'...and the care assistant said, 'Oh!...he is fixated on something on the wall'. And I thought, 'Oh no, I think there is more to it than that'. And I went over to him and there was no response at all. And he was just gasping...that sort of way....[she demonstrates 'cheyne stokes' breathing] ...like that. We sat there for the fifteen minutes and he died at a quarter past twelve.'* *[Night nurse, CLG. 2, pg.6]*

Being able to talk in this way about the subject of death and dying helped to make dying part of the nursing home culture. Staff were gradually recognising dying as a process with different stages: the gradual deterioration within the context of the prolonged dwindling (Lynn & Adamson 2003); the gradual withdrawal from eating and drinking; the increasing weakness; the 'mottling' of the skin as a result of peripheral shutdown; and the subsequent change in the breathing and change in the force of the pulse, as vital centres within the brain become less oxygenated. With the trained nurses speaking about these things, care assistants were learning directly from colleagues.

> *'..and we noticed that his peripheries were really purple…and as we turned him over he had that sort of mottling...that purple mottling…and I just thought, "I think he is going to die"'.* *[NN, CLG.2, pg.4]*

The hospice movement's emphasis on the importance of the family being the unit of care, and not just the patient, has been fundamental to its philosophy for end-of-life care (Baines & Saunders 1983). Many staff in the CLGs did not realise the importance of pro-actively talking to and supporting families through the dying process For those families with whom it was easy to form relationships this wasn't an issue. But for many, staff needed encouragement to see the families' needs alongside those of the resident in end-of-life care. This needed to be taught and demonstrated.

> *'"You know there is really no more nursing care you can give to the resident, apart from what you are doing, and it is the relatives that need [the care]."'[N, CLG.1, pg.14]*

Sharing the difficulties of speaking to families also acted as a way of teaching how to reach out to family members who were in denial of the situation. Not only was the project reminding staff about the importance of speaking to families; reflecting on doing it helped to internalise the learning.

> *'The other thing I learnt from [this situation] was the difficulty that sometimes you have to get through to the family. I mean, I spoke to her daughter on a number of occasions*

> *and she couldn't accept the fact that she was serious. And she said, 'She has had two strokes before and she's having another one – she'll be fine!' and, I knew the brother was in London and I kept saying to Sheila, 'Look, what about your brother?' ....and eventually I had to speak to the brother on the phone. He phoned me one day and I said, 'Look I think you should come up this week-end'. 'Oh well, I don't know. I am up in a couple of weeks'. And I said, 'I think you should come up this week-end'. And I had to be actually quite firm with him. And fortunately, he did...he came up and spent a lovely week-end because they brought the grandchild and she played with the grandchild and she smiled and everything just before she died. And I am so glad because it was only a couple of days after that that she [deteriorated further and then] died. But it was very, very difficult to speak to these people.'* *[NM, CLG.4, pg.12]*

This was one of the last CLGs done at NH1. In this particular situation, this experienced nurse manager had noticed that the resident was not just going to 'bounce back' as the daughter felt. She realised the importance of raising the issue in advance with other members of the family. Even though management of NH1 had been apprehensive about addressing a more 'open' communication about death and dying, the CLGs, as well as addressing symptom issues, were also giving a greater freedom to begin to address some psycho-social issues of end-of-life care.

In NH2 there was a greater degree of 'openness' about death and dying coming from the leadership. Many of the staff in NH2, however, carried unresolved grief that blocked their ability to recognise dying and to be open with residents who tried to speak of death. The nurse manager found that the CLGs provided time to highlight her values around end-of-life care and how she wanted end-of-life care developed in the nursing home. Staff were encouraged by their nurse manager to see other residents as an important part of the nursing home community when another resident died. This addressed issues that had been raised in the focus groups where staff had not known how to handle other residents seeing a coffin. The CLG was providing an opportunity for the nurse manager to suggest how staff should act when a body was being removed from the nursing home.

> *'"If Violet is vying with her zimmer – then let her out. If she meets a coffin she knows what coffins look like! Let her out. All we need from my point of view that they keep things back is if they feel it is difficult for them. Otherwise there is no reason....all that*

> *the residents had to be told was that the undertakers were here with [Julie]."' [NM, CLG.8, pg.28/29]*

During the CLGs, there was considerable teaching on medication for end-of-life care. Most nurses, like their GP colleagues, thought that opioids were the only drugs one needed to control symptoms in the last days. Agitation in a dying resident was treated with an opioid rather than an anxiolytic. However, my working alongside staff in facilitating and advising about symptom control helped them to understand and put into practice the use of differing palliative care medications. The CLGs were then a forum for this knowledge to be shared.

> *'"He was having the Diamorphine when we first put the Fentanyl up, waiting for the Fentanyl to take effect and also for breakthrough pain and we didn't know how much Fentanyl he needed to begin with so we started with a 25mcg patch....and then we put it up to 50mcg and then obviously by that time the pain was getting a lot worse and he was still taking the Diamorphine, so it was just at the end that he went up to the 75mcg. I think the Midazolam was a good thing for him."' [NM, CLG.3, pg.14]*

Although the CLGs addressed pain control if a resident was dying in pain such as in the above example where a resident had a gangrenous wound, often pain was less of a problem than agitation in the last days of life. However, care assistants often used the CLGs to draw attention to residents they knew who were not necessarily dying but in pain. They saw the CLGs as an opportunity to highlight problems, especially pain, that they felt weren't being adequately addressed. It was important to encourage the care assistants to take this aspect of their role seriously and to continue to 'nag' a nurse if pain was not adequately controlled.

> *'"... it is really important that...if pain is not being managed, to keep on nagging that someone is in pain. Care assistants do tend to know the residents the best, because you do the most caring."' [JH, CLG.8, pg.3]*

There is considerable evidence of uncontrolled pain in nursing home residents (Teno et al. 2001; AGS 1998; Flaherty 2001; Stephenson 1999). The continual mentioning of pain problems resulted in separate tutorials on pain assessment and its management. The majority of residents in the nursing homes had varying degrees of dementia, so pain *assessment* was more complex than for cancer patients within specialist palliative care. Many people were not able to describe their pain, let alone talk about its severity. Instead, it was necessary to look at the literature for alternative assessment tools, where observing a change in normal behaviour as a result of pain was more appropriate than a cognitive assessment tool. This resulted in a specific pain assessment and management tool being designed and implemented by staff in NH2.

Constipation was an issue that came up on several occasions. Often there was a sense that if someone was very ill and dying, staff did not want to disturb them and so no attention was given to bowel care. This was never a problem if the resident was not constipated before they deteriorated. However, on several occasions residents were severely constipated. On one occasion a decision, was made to give a suppository to try and help clear the rectum of a resident who although slowly dying was continually leaking faecal fluid. It was met with a challenge at the CLG following the death.

> *'"It was absolutely horrendous. If the son was up to visit him that day, he wouldn't have been able to sit with him in that room." ... "So what was the point of doing that?"' CA, CLG.2, p.8]*

I was pleased that the care assistant concerned felt she could challenge my practice. A long explanation on 'faecal impaction' followed. The staff had been embarrassed by the smell but up until then, few had properly considered the consequences of faecal impaction. No other resident dying in this nursing home ever had this problem while the study continued. The discussion even stimulated a reassessment on the recording of residents' bowel action.

6.4.2 Mutual understanding of end-of-life care: 'developing understanding'

The CLGs were not just sessions where issues about end-of-life care were 'being taught'. There was evidence that staff were engaging with the learning. The sessions became a place where increasing understanding of end-of-life care was expressed. The sessions gave opportunity for wider discussion on differing issues and staff showed an increasing willingness to share their own values about end-of-life care and how they wanted it practised.

The number of deaths in both nursing homes[44] during the study was highlighting the increasing frailty of residents being admitted to nursing homes. The rather 'rehabilitative' culture concerned with 'living', where death and dying was often hidden away, was being challenged. Gradually staff were realising the importance of recognising a changing role of nursing homes.

> *' "..and as someone else has said [residents] are very much more frail when they do come into nursing homes; therefore their life expectancy cannot be as high as it was even five years ago." '* *[NM, CLG.1, pg.12]*

> *' "...it's just interesting [what] you're saying there...nursing homes and old folks home...I would never have related [care] to their last couple of years or whatever. Whereas the hospice I would. But you saying that...that totally gave me a completely different insight.... I always thought you went into a nursing home because there was nobody [at home] to look after you"'.* *[CA, CLG.10, pg.23]*

Nurses in the CLGs showed increasing awareness of their important role in end-of-life care. This role and the importance of recognising dying were mentioned a number of times across the nursing homes as being pivotal in order to orchestrate good end-of-life care. Even when a nurse had not spoken up and had 'gone along with the doctor', it was

---

[44] Fifteen residents died in NH1 (25-bedded NH); twenty four residents died in NH2a (41-bedded NH)

felt that being able to verbalise feelings about what one should have done was embedding new thoughts of how to do things.

> *'"..my instinct was that he was going to die because as soon as I had seen this mottling on his back I thought, 'Now that is his peripheries'...you know. I really did think...and I nearly said to the doctor, 'Don't you think he is going to die?'....but I don't know why [I didn't]. Maybe I thought, she knows best! ...I wish I had actually....I wished I had afterwards. I should have."'* *[NN, CLG.2, pg.7]*

There was a sense that nurses were prepared to take on a more significant role in end-of-life care and decision-making. By encouraging reflection after the event, people learnt more readily the importance of taking responsibility, and to anticipate more confidently dying within the deteriorating trajectory. It happened in both nursing homes:

> *' "You see in the past what has been different is that the doctor has suggested something and we go along with it.... That's the big difference. We should now be thinking, 'Right, what is our opinion of what should be happening?"'* *[N, CLG.3: p.26]*

Learning to cope with death and dying enabled nursing staff and nurse managers to be more questioning about end-of-life decision-making. The groups helped staff to think through situations together, and to discuss how they might want to take end-of-life care forward and address issues such as the ethics about end-of-life decision-making.

> *' "I mean perhaps we should be going to the family and enquiring...."Were your Mum...to...get pneumonia....? ...Perhaps people like Michael we would say, 'Now then....what is appropriate to be doing."'* *[NM, CLG.8, pg.8]*

When a resident died suddenly, it became apparent that a majority of nurses struggled to know what to say to relatives on such an occasion. Often there was a delay in telling relatives. Staff felt uncomfortable about giving bad news over the phone. Instead, staff would ask a family member to come to the nursing home because the relative was very ill and then be told that the resident had died. As staff talked more openly about death and dying so they began to realise that gentle honesty was often the best policy. Those staff who admitted to not knowing how to manage such a situation, or felt embarrassed about the 'white lies' they sometimes used, were gradually understanding that being honest was in the end a lot easier.

> NN *'So I thought I'd ring her in the morning and tell her that he wasn't well and to come in! But, matron suggested that I just...you know just told her straight...that he had died. Which I wasn't happy about doing...because I had never told anybody over the phone that somebody has died. Particularly when they are on their own.*
>
> JH *So how was it when you phoned her?*
>
> NN *I said, "Hello Chris, this is E.....you know I have got some very bad news for you". And she said, "Dad didn't make it" And so I said, "No" But she was very nice – very composed which I was very surprised about...' [NN, CLG.2, pg 8]*

Where there was good advice on how to do things' it became a good learning situation for the staff nurse concerned. In addition, as the incident was related, those present came to know and understand the nurse manager's values. Being challenged to phone the relatives by the nurse manager on this occasion was a hugely positive experience even though the night nurse did not want to do it. She thought it would be better if the relative came up to the nursing home and was told face to face. How much this was an unconscious 'avoiding' of telling the relative herself, and how much it was out of genuine concern for the relative, did not get 'picked up' in the session. Nonetheless, when she made the call, the night nurse did give a 'warning shot' to the daughter that she had some bad news. This had the appropriate effect with the daughter confirming that her dad "didn't make it". For the staff listening, this discussion was valuable for the time when they themselves might have to make a similar call. The value of the 'experience' was also reinforced when the relative phoned back to personally thank the nurse.

What was important about the CLGs was that all staff were being given the opportunity to learn together, not just about the resident's needs, but also about those of the family. It was rewarding to hear staff say quite spontaneously *in* the CLGs what they had been learning from the impact of the study.

> *'"Yeh! I think that is something that I have picked up with this...project...is the relatives. You know, appreciating Hilda's daughter, you know...because you can get involved in the resident...you are caring for them, and you say, 'Oh yes, come in' but when it comes to talk...I used to think I'll just get out the way and go away. But ...no, no, I'll stand and I will speak now rather than just going on. I'm just sort of thinking about it now."'*
> *[CA, CLG. 1, pg.14]*

Once learning is internalised, it is more likely to impact on the individual's practical work (Johns & Freshwater 1998). Because there was this sense of analysing and reflecting back on a resident's death, staff in the groups (including myself) were gradually beginning to critically analyse a number of assumptions and issues. These are discussed in the next section.

6.4.3 Critical knowing – 'challenging the status quo in end-of-life care'

In some of the CLGs there was a clear indication that those present were beginning to re-think critically the care given to those of their residents who were dying. Subjects were being discussed that began to challenge end-of-life care in the nursing homes. One such aspect was the use of the word 'dying'. More often than not, euphemisms such as 'more poorly' were used in preference (see Section 5.3.2). This resulted in staff not understanding the full situation and even in some occasions perhaps being in denial about what was going on.

> *CA1* *We were told that she was deteriorating, but we weren't told she was actually 'dying'. So I mean...that was a shock to me because I've just been off for two days, I have just come back to-day.*
>
> *JH* *So, it is something about using this word 'dying' that is quite important?*
> *CA1* *It is for me!*
>
> *CA2* *...for everyone to use the word 'dying'.*
> *N* *I thought she was just declining.*
> *CA1* *Even when you think someone is deteriorating, you think they are just going to 'bounce back'.*

CA2 *For me 'deteriorating' & 'dying' are two different things.* *[CLG.5]*

This discussion, started by a young care assistant, had an enormous impact on the group. Not only was it about using the word 'dying', but it also shed light on how some of the staff appeared to be reacting or not reacting when a resident was dying. Froggatt (2001a) reports that using the phrase 'being poorly' sent messages to members of staff and relatives that a resident's condition had changed. However, in this study, and more specifically in he CLG above, this was often not the case. Not using the word 'dying', and thinking that a resident was just 'deteriorating' or was 'more poorly' and would therefore 'bounce back', meant that staff often lacked a deeper involvement in end-of-life care. Not being aware that someone was dying compromised quality of end-of-life care. In this situation the resident had fallen while in the toilet cubicle because of her weakness. This young care assistant had continued to say that *if* she had known she was dying, she would have given her a commode by the bed and not encouraged her to walk to the toilet.[45] Young untrained care assistants will not have the experience to know instinctively when a person is dying and may continue the same care unless told otherwise. They often have had no training on the subject of death and dying (Komaromy et al. 2000). More worryingly, it was also the staff nurse in this scenario who was apparently unaware that the resident was dying.

'Bounce-back' as a phenomenon contributes to the difficulties of recognising dying in the old and frail (see Section 5.3.4). 'Bounce back' is a common occurrence and a phrase that I had not heard prior to working in nursing homes. For those who find death and dying difficult to cope with, or for those with a tendency to strive to keep a very frail elderly resident alive, there is a danger that always hoping the resident will 'bounce back' can be used as a form of denial. Not acknowledging that the resident is dying can often mean that an important event such as dying then goes unmarked. If dying is not diagnosed (Ellershaw & Wilkinson 2003), then dying runs the danger of being

---

[45] This is further evidence of the 'rehabilitative' culture.

designated as the 'bounce back' phenomenon with staff hoping that they 'won't die on my shift'.

i) End-of-life decision-making

Consideration of the ethics of end-of-life decision-making plays an increasingly important part in nursing home care (Vallis & Boyd 2002). The use of antibiotics for chest infections and especially pneumonia in frail older people with advanced dementia was challenged in a number of the CLGs. Gradually, as the CLGs continued, staff became more vocal.

> *'"I worry about the amount of antibiotics given in this home….I know that there are different situations, but I really feel that certain people whose condition is not….hasn't got a good quality of life… I feel we are just prolonging the agony… ….I do worry about the amount of antibiotics…when I am taking report – I am only in one night a week – there will be six or so people each week on a new antibiotic…for the 4th…5th time."' [NN, CLG.8, pg.7]*

Antibiotics were not the only resuscitative measure that was queried. There was, appropriately in my opinion, no resuscitation equipment in either nursing home. However, some care assistants found it difficult to accept that someone with advanced dementia should not be resuscitated if they unexpectedly collapsed and died from a heart attack. Little discussion about death and dying meant a lack of anticipation of such an event. Advanced dementia was more often considered a social problem rather than a valid medical condition from which people died.

> *'"And resuscitation and all that! I thought…it's your first instinct…usually…if you were sitting at home and your mother was [in a nursing home]…what would be the first thing you asked the nursing home? "Did you try and revive my mother?" Well, I would.' [CA, CLG.9]*

Residents were seen by many care assistants as 'family' through their long involvement in caring for them. Many care assistants personalised the care given to residents, comparing it with what they would have wanted if it had been their mother or father who had died. Unspoken conflict between different goals for end-of-life care and the different values and beliefs held by staff was present. Some staff found it difficult if a resident died who had not been seen, in their minds, as being 'ready to go'. Some care assistants did not see looking after frail residents, suffering from multiple medical pathologies including advanced dementia and requiring 24-hour nursing care, as heralding the need for palliative care.

> '"*I always thought you went into a nursing home because there was nobody there to look after you.... I would never have related it to the last couple of years or whatever. Whereas the hospice I would.*"' *[CA, CLG.9 pg.12]*

The rehabilitation culture within nursing homes meant that death and dying was pushed to the periphery.

ii) Natural dying

There were a number of occasions during the CLGs where staff highlighted the gradual withdrawal, first from food and then fluids, which sometimes appeared to occur naturally when a frail elderly resident was dying. I observed that this was a different process of dying compared to what I had witnessed within specialist palliative care.

> '"*... And she was starting not only [not] to eat but not to drink. And em...you know...when I came back the situation was the same more or less. But she really did go down very quickly at the end....She had been seen by the GP. There was nothing specific apart from...going onto Lactulose because I was a bit concerned her bowel might be loaded..... The Wednesday she had a bath and was a bit brighter. On Friday I felt she was quite terminal...leave her in her pyjamas in bed and see how she goes. She seemed to be quite settled on the Friday...I came in on the Saturday and spoke to [the relatives] and said that she had deteriorated.....*"' *[N, CLG.5, pg.6/7]*

This resident died very peacefully 36 hours later. The nurse manager in NH1 also discussed similar thoughts about this gradual withdrawal first from food and then from fluids in the last weeks of life of residents with advanced dementia. This natural dying of older people in nursing homes was appropriate and one that often required less medication[46]. The CLGs gave us the opportunity to consider end-of-life care in nursing homes more critically. I was being challenged by what I saw as a different trajectory of dying and realising that one should not impose a model from specialist palliative care, based on care of people dying in mid-life from cancer, onto that of older people dying at the end-of-life in nursing homes.

On one occasion, the use of an opioid for a resident who was imminently dying, was rightly challenged by a staff nurse in a CLG session.

> *'"I felt she didn't need oramorph – she didn't appear in pain. But even if she did settle when [the GP] came in I wanted something that she could have if she needed it. So she had Diazepam 2mg……I know you were going along the lines of oramorph but I thought I don't want to 'zonk' her out completely and not have her drinking at all. Whereas the Diazepam – a small amount settled her and it was enough to settle her to let her lie……and Diana & Sue sat and read to her all afternoon."' This resident died 12 hours later. [CLG. 5, pg.19, 21,22]*

It was encouraging to witness the skill in caring for older people being expressed by an experienced staff nurse. Morphine was often what GPs wanted to prescribe and often what came first to my mind because of my work in specialist palliative care. However, I realised how important it was for this nurse to be challenging its use. An opioid in an elderly dying resident, especially someone with advanced dementia who had no pain and was likely to be dehydrated, was a significant threat to a peaceful death; the drug of choice being an anxiolytic.

As well as being more 'natural' (McCue 1995), some deaths in the nursing home also appeared more autonomous. By autonomous I mean that I believe that a resident, sometimes by default, died independent of the medical profession. This more autonomous dying was not necessarily detrimental for the resident. Older people in nursing homes see dying as a relief (Singer et al 1999). On occasions it appeared that

---

[46] Current thought is that there are increasingly fewer 'thirst' receptors in the blood vessels of older people, especially as they face the end of their lives. This allows natural dehydration in the dying phase to bring on what is meant to be a very comfortable way of dying from a uraemic coma [personal communication – geriatrician].

residents knew they were going to die and some even appeared able to decide when it was 'time to go'. Many patients dying in a hospice where there is a more active medical presence become dependent on their doctors.

> *'"...she said to me, 'I think I am going to die' and she [then] started talking about her father."'* [JH, CLG.4. pg.3]

It appeared that even residents suffering from advanced dementia knew they were dying.

> *'"I think – working with her quite a lot in the past – I felt that she was quite aware of the fact that she was dying. She was quite, quite able to articulate that. And certainly when we chatted altogether with the GP and staff nurse it came across that she was not afraid of death."'* [NM, CLG.8, pg.18/19]

iii) 'Being with' the dying

For older care assistants, sitting with someone who was dying was natural and they were frustrated when this didn't happen. Staff were beginning to challenge management about the time needed to care for dying residents.

> *'"And that's what I say about Ethel – it was different – and I have to say that everybody got time to be with her. It wasn't just like the one floor – everybody from both floors took an hour about...that was nice."'* [CA, CLG.8, pg.34]

In this incident, the nurse manager had arranged for a higher staff/resident ratio than normal in the home so that staff were able to spend time during the dying phase to be with the resident.

With the increasing opportunity to reflect on practice, some aspects of care were being challenged and change was beginning to occur. However, top management struggled to recognise the increasing burden on staff in caring for the increasing number of deaths they had to cope with and the emotional burden involved. Even though statistics and research (Sidell et al. 1997; Teno 2003) report that nursing homes are becoming places where older people die, it is still difficult to encourage a change in resources in order to support their staff.

6.5 SUPPORTIVE & COMMUNICATIVE ROLE OF THE CLGs

There was evidence that, as well as fulfilling an educative role, the CLGs fulfilled both a supportive *and* a communicative role amongst team members. Some staff, one care assistant in particular, really benefited from being able to open up about the death of his father during one of the CLG sessions. The nurse manager had tried unsuccessfully to encourage him to go for professional counselling; he attended the CLGs regularly and gradually opened up about his own situation that enabled other staff members to realise his own personal issues with death and dying. Up until the action research study, this carer had never been involved with a dying resident despite being in the nursing home for $2^{1}/_{4}$ years. Yet, he himself even asked to sit with a dying resident during the study. There was a sense that the CLGs were enabling staff to recognise the importance of the 'lifeworld' (Kemmis 2001; Habermas 1987a) of those caring for dying residents. This is a feature that will be taken up again in Chapter 8.

Many care assistants found a release in not keeping things 'bottled up'. The CLGs provided a legitimate opportunity where time was given to share 'feelings'. The word 'feelings' was a word repeatedly used in the evaluation questionnaires.

> *'"I feel it was really helpful to be able to talk about our feelings before and after. It was a great relief"' [CA3, evaluation questionnaire, NH2a]*

> *'"Being able to discuss events leading up to death and death itself. Realising that one is not alone with these feelings"' [CA1, evaluation questionnaire, NH1]*

> *'"It gave me a chance to express how <u>I</u> felt after a resident had died."' [CA1, evaluation questionnaire, NH2a]*

Caring for frail residents over many months strengthens an emotional bond between resident and carer that is unique to care homes (Hanson et al. 2002). Residents who strive not to be a burden appreciate such a bond (Singer et al. 1999). It was not unusual for care assistants in both nursing homes to become very attached to certain residents. With this close relationship came a greater sense of personal loss, and revealed the depth of caring that many staff gave willingly. This quality of caring for older people dying in nursing homes is important. How much staff feel supported in this work is likely to affect the quality of care given (Stoter 1997).

Those CLGs held after a resident had died ‘suddenly’ were different from other sessions. The discussion that took place in these sessions [CLG 5, 6 & 8] had a far greater emphasis on staff needing to be able to talk, and to be able to share the awfulness of certain situations. There was a sense that re-telling the story formally to others gave staff permission to ‘let go’ of the burden.

> *‘“...The RGN just said, ‘Quick help me, he has fallen’. That was as we walked in the door. And he was actually....he was lying on his back with his head underneath the arm of the chair. I don’t know how he got into that position....but, eh...we checked him over...oh, he was so distressed. So three of us just lifted him into bed. He was so distressed. He really was. And we noticed that his peripheries had that sort of mottling...that purple mottling...and I just thought, “I think he is going to die.”’ [NN1, CLG.2, pg.4]*

There was the need to try and make sense out of the situation for those who had been faced with such an ordeal. Some nurses carried a sense of guilt when they felt there was something that they might have done differently, even thinking that perhaps they could have been able to do more.

> *‘“But I must admit I felt... I have to be honest...I felt a bit ....like...she died without us being able to do something for her. I did feel initially that maybe I should have...could have done something else, but there wasn’t anything else to do.”’ [N3, CLG.1, pg.13]*

Part-time and night staff in particular, found the communication aspect of the CLGs extremely helpful. The CLGs could have unwittingly been a substitution for the handover that many staff did not get the opportunity to contribute to. The opportunity to be able to raise issues and 'tell the story' helped to fill the emotional gap as well as encouraging learning from within practice. Many appreciated the sessions because of being able to find out in detail what had happened to a specific resident and how they had died. After a very difficult situation where a resident reacted to a sedative being used in the last few days of her life, one of the night staff nurses came along to the session specifically in order to find out what had happened in the end. This nurse in particular commented on her final evaluation form questionnaire how helpful she had found the session. She had needed to know that the resident in question had in fact died very peacefully after further expert opinion had been sought.

> *'"It was helpful to attend the de-briefing so that I could hear that she had become more settled at the end of her life even though I didn't see her."' [P/T1, NN, evaluation questionnaire, NH2a]*

For others the sessions gave opportunity to build teamwork. It was not as though staff did not know each other; however, the sessions gave a different dimension to the previous informal sharing about the death of a resident. Meeting formally, with the CLGs being facilitated by a nurse experienced in palliative care, appeared to strengthen teamwork in a more professional way across the different staff groups; not just between night and day staff but across the range of different staff in the home.

> *'"A chance for staff to open up to each other, day staff including cleaners. Night staff – to get to know day staff even better – hopefully to the residents' benefit."' [P/T2, NN, evaluation questionnaire, NH1]*

The sessions were open to any staff member who wanted to attend including domestics and the cook/s. The exploring together of feelings and different ideas about how death was managed provided an opportunity for staff to communicate on a different and more important level than normally occurred at coffee breaks or in the pub. One nurse manager specifically found reading the transcript of a CLG that she had attended gave her a clearer insight as to how one of her staff had been affected by the death.

> *'"Jo, I never realised until I actually read the transcript of the [CLG] we had on Thursday, how badly Mary had been feeling."'* *[NM, fieldnotes. NH2a]*

The emphasis on both the supportive and communicative outcome of the CLGs is likely to be due to a number of different things. However the absence of an appropriate regular handover time for *all* staff may have influenced the degree to which the sessions fulfilled these particular roles. Hopkinson (2002) found that the nursing handover had a hidden benefit of support for nurses caring for dying people in hospital.

After a year of being in NH1 and NH2a, the CLGs were evaluated along with other aspects of development within the nursing homes. In order to try and reach as many staff as possible, an evaluation questionnaire was distributed. This next section looks at the analysis of this evaluation.

6.6 EVALUATING THE COLLABORATIVE LEARNING GROUPS

In order to bring an objective measure to the collaborative learning groups, a questionnaire detailing the different initiatives on end-of-life care was sent to all staff who had been involved in the project (see Appendix 8). The transience of staff meant that the number of questionnaires returned was limited. In NH1, only six out of the fourteen staff who had been part of the exploratory phase and taken part in the CLGs remained. Nine questionnaires were sent to current staff and to those who had left a contact address; seven were returned (78% response rate). In NH2a there was smaller staff turnover; thirty-five evaluation questionnaires were sent out. There was a 54% response rate but not all the questionnaires were complete. Out of the usable questionnaires returned from NH1 and NH2a, twenty-two evaluations concerning the CLGs were complete. 45% of staff rated the sessions between 8-10/10 (see Table 6.4).

Table. 6:4: Evaluation score for the CLGs

	Trained Nurses				Care Assistants				No. of staff responding to evaluation of CLGs
Score	**10/10**	**8/10**	**6/10**	**4/10**	**10/10**	**8/10**	**6/10**	**4/10**	
NH1	-	1	3	-	2	-	1		7 staff
NH2a	2	2	1	4	3	-	3		15 staff

Four nurses rated the CLGs as 4/10; two of these nurses commented that they didn't feel they needed support as they felt that a resident dying was a natural part of life; they probably had missed the point of learning through reflecting on practice. One of these responders found that her personal issues with grief and loss made it difficult to talk about death/dying. She did not engage fully with the project, although enjoyed the more technical knowledge development on pain assessment and management. The project may have exacerbated tension in those whose unresolved grief prevented them from moving forward.

Initially, not all staff were confident about the CLGs when they were first introduced following feedback from the exploratory phase. One of the nursing home owners of NH1 admitted to feeling apprehensive about the groups and after one particularly protracted death she queried whether the staff wanted to be reminded about it. This was not unexpected in the closed culture surrounding death and dying that was present in this nursing home prior to the project.

> '"…. *I have to admit that I was very apprehensive about these reflection times. When you told us you were doing the last one I thought, 'I'm not sure this is a good idea! Surely after a death people want to forget it and move in. They don't want to be*

> *reminded about it.' However, I have changed my thinking on it..."'* *[NH owner, NH1, fieldnotes, 14.11.00]*

One of the nurse managers who came regularly felt the sessions gave an important opportunity to show staff that they were valued for the work they did. Being involved in the groups helped her understand more fully how staff were really feeling over the death of a resident. It required the nurse managers to be supportive of the groups if they were to work well.

> *'"[They] gave a valuable opportunity to the manager to hear first hand from a group of workers their thoughts and feelings on a death. It gave scope for reflection on practice and provided a safe environment for staff to make their views known. From this future training/planning could be formulated. It also valued staff which I feel is extremely important in this field of work".'* *[NM, evaluation questionnaire, NH2a]*

One area of conflict that arose with the CLGs, both in the returned questionnaires and in fieldnotes, was the time allocated to a session. It had been agreed that they would last 45-minutes which I felt was the minimum for a session. In NH1, where it was difficult to influence the 'task-orientated' care culture, the nurse manager found the time given to the session detracted from the care of *current* residents:

> *'"I feel many 'sessions' were very lengthy and therefore time was not being spent on the current residents whose needs were – at the time – greater."'* *[NM, evaluation questionnaire NH1]*

The supportive nature of the CLGs for staff was directly challenging this focus on 'getting on with the work'. In the same nursing home, one senior nurse felt the sessions 'were often rushed'. One could understand that if handovers only lasted ten minutes, forty five minutes for an experience-based learning session seemed a very long time when it was about one resident who had died and who therefore no longer needed care. In this home, there was admirable attention to the physical care of current residents but little sense of how deaths actually affected staff. This difference of opinion was never resolved but the senior nurse who felt sessions had been rushed continued to hold the

CLGs after I left the nursing home. Four months after finishing the study in NH1, I interviewed the owner about the impact of the CLGs:

> *'"Those [CLGs] were good! That has been the big thing, and they have...we have had one since the last two [residents died]...I think it was Jane that got it organized... that is one thing that I would definitely like to encourage, because I think that helps. I think it gives the care assistants in particular, and some of the RGNs...er...the confidence that they are doing the right thing. It is one thing 'thinking' you are doing the right thing – it is another thing 'knowing' you are doing the right things...It is reviewing that depth. And if somebody has got a feeling that, 'well, I think that we should have done [such and such]..' they get the chance to say it. I like them to be involved....you know...and it makes me feel that they are being given the chance to say their bit...everyone wants to say their bit".' [NH Owner, NH1, evaluation interview]*

There was a considerable eagerness to have the opportunity to learn through the CLGs. This could have been for a number of reasons, namely: that reflecting on a resident whom staff had cared for made it more relevant to the immediate practice of the nursing home; that having a person come from the Hospice to teach helped to value the work that staff did in the nursing home; that there were senior nurses in both nursing homes who were very at ease and enthusiastic with this type of learning, which encouraged the rest of the staff; and, finally, that the 'oral' tradition of untrained care assistants was respected. During the sessions, care assistants appeared to feel confident to share their experiences specific to residents they had looked after; however, at the few tutorials that I had been asked to give, engaging them was much more difficult. The interactive CLG sessions, where discussion with staff about the care given to a dying resident whom staff had known well and had cared for over many months, held their attention.

Staff appreciated the opportunity I took to 'work alongside' them when a resident was dying, and were glad to be able to talk over issues that they felt they needed advice on. This meant that I often knew the resident quite well myself prior to the discussion at the CLGs, which then gave me insight into what we might want to address before each session. One trained nurse highlighted the importance of having someone with experience in palliative care to lead the sessions.

One of the major purposes of the CLGs was to encourage the linking of theory with practice. One could see from the increasing critical thought as staff became more familiar with the process of the CLGs that staff were able to reflect on their own practice when encouraged to do so.

> *"Useful to reflect and learn from experiences" [N1, NH2a: evaluation questionnaire]*

> *"Having a 'specialist' on hand was so good in helping staff including myself feel that the best was being done for a resident. Knowledge was increased, practical skills enhanced and resident care improved." [CA4, NH2a: evaluation questionnaire]*

Having the CLG sessions take place within the nursing homes allowed more staff to attend than if a course had been held at the Hospice. This is not to say that this is better. It could be argued that both are important but the CLGs certainly met a need in staff in their care of dying residents.

6.7 REFLEXIVE DISCUSSION

The CLGs were bringing to the surface interesting information about end-of-life care. I was also beginning to understand more clearly how the history of both nursing homes was impacting on the way we were/were not able to develop end-of-life care further.

This section considers a couple of major themes that were emerging, and, how these were to influence the focus of the action in NH1 and NH2a. As in the previous chapter one theme deals with the process of doing action research and one theme relates to death and dying in nursing homes. Thus, the two emerging themes are:

- issues of power and authority when attempting to change practice
- anticipating the process of dying as an important part of ensuring a high quality of end-of-life care

What follows is a reflexive account of how I became aware of these issues. It also takes forward the narrative of how the actions were developed in the study nursing homes.

6.7.1 Issues of power, authority, and change

In Chapter 5, it was highlighted that Meyer (2000) suggests participation as an important element of action research (see Section 5.4.2). Meyer also discusses the importance of a '*democratic impulse*'; that is, that power is shared between the researcher and those involved in the action research in order to learn from one another. Issues of power and authority are now discussed in relation to bringing about change in nursing homes.

Staff in both NH1 and NH2a were feeling more supported and empowered with their increasing knowledge of end-of-life care as a result of the action research. However, despite an eagerness by the management in NH1 to be part of the study at the beginning, I was realising a subtle change in their attitude towards the action research. Even staff in NH1 had noticed:

> *'[It] was welcomed enthusiastically initially by management and staff but the management soon lost interest and the support was not forthcoming from them to implement changes which would benefit caring the dying in [NH1].'*
> *[N3, evaluation questionnaire, NH1]*

The nurse manager did not always share the staff's enthusiasm for the research, the CLGs and the developing knowledge about end-of-life care. I had naively accepted the nurse manager's excuse of 'busy-ness' as a legitimate reason for not continuing with our monthly meetings together; and had reasoned to myself at the time that it did not matter since we seemed to be getting on well. However, without these regular meetings I had lost the opportunity to share concerns. This then became a no-win situation. Despite the nurse manager saying she was too busy to meet more formally, it appeared that my increasing rapport with the staff made her feel threatened.

During the exploratory phase, one of the differences of opinion between many of the staff and the management about end-of-life care had been to do with the closed communication culture. The management of NH1 felt that any greater recognition of or openness about death and dying would upset residents in the home. The owners of NH1 had told me they had no health care qualification and that they relied on the nurse manager for her expertise. However, the nurse manager was uncomfortable with a more person-centred approach to the organisation of care (see Section 5.2.1). The innovative aspects of palliative care that encouraged a less task-orientated approach and a more inclusive approach towards staff were quite alien to management. Nonetheless, the owners of NH1 and the nurse manager thought their way was best.

> *'The conversation switched to the [number] of deaths that had happened in NH1 and how perhaps the other residents might be finding it. Again the nurse manager and the owners were unwilling to recognize that a couple of residents with a degree of dementia could be 'aware'...However much I tried to explain, there was this strong sense that 'they know'. I felt their comment paternalistic... As I write this I feel exasperated and feel that it is very likely nothing will change. The owners and the nurse manager feel very powerful and I feel I have no real dialogue with them despite my trying – it feels so much them and me.' [Fieldnotes, 07.02.2001]*

During the process of doing the research, we had found a way to support staff and develop knowledge about death and dying through the CLGs, but I felt that the team itself would find it difficult to develop further after I left without greater openness and more support from the management.

Three staff had shared with me their reasons for handing in their notice but these were not the reasons given to management. Some further staff had mentioned to me that they were unhappy and they too were thinking of leaving; they said they wanted to feel more valued for what they did. I wanted to draw management's attention to the matter because these staff were very committed to caring for older people in nursing homes.

I had recently read an article about 'grasping the power' in critical action research (Duffy & Scott 1998)[47] in order to help identify an issue that might be blocking change. An opportunity came up after a CLG when the nurse manager and I were in the office.

---

[47] An article that I now find quite alarming.

She had just told me about another staff member leaving[48]. As the nurse manager and I sat in the office together, I posed the question as to why she felt staff were leaving. We talked together about the need for staff to be listened to and to feel supported especially when residents were so frail. Unfortunately, my concern was misconstrued and the nurse manager reported me to the owners of the nursing home. My fieldnotes capture the uncomfortable experience of a meeting with the owners:

> *'My remit in their eyes was to develop "palliative care" not to start criticising the organisation. I admitted saying to [nurse manager] that I felt she had a greater allegiance to [the owners] than to her staff and I worried for the support of staff because of this. Because [the owners and the nurse manager] had worked together for 17 years they had formed a strong working relationship. My saying this to the nurse manager was like saying she wasn't good at nursing, as far as [one of the owners] was concerned. I tried to suggest otherwise and was only concerned that the staff felt supported and appreciated. Their reply to this was: "matron has to be apart from the staff". I agreed to this... but added that it did not mean that she should not empower them and support them. [Fieldnotes, 22.02.2001]*

The meeting was not comfortable. One of the owners suggested that I might be a threat to the nurse manager. As a first time action researcher, I never saw myself as a powerful person – many times, going to the nursing homes, I would feel extremely nervous. I had seen the owners and nurse manager as all powerful and very much 'in charge'. I now realised that the nurse manager might be more threatened by new things than I had first realised – the idea of more person-centred care plans being advocated by the deputy nurse manager as well as the action research study.

The experience of the situation described above was a salutary lesson in maintaining a 'democratic impulse' and keeping communication open with *management* when undertaking action research. By coincidence, at that time, I was reading a non-academic book that I would like to refer to as it helped to throw more light on issues to do with power and change, and what might have been happening in NH1 in particular. In the

---

[48] The owners of NH1 had warned me prior to commencing the research that they had gone through an unsettled time regarding their staffing since taking over the nursing home but I had not realised that nearly half the staff had left until after I arrived. Only after being in the home a number of months did I begin to realise that many staff were still unhappy.

English language there is little differentiation between 'power' and 'authority'. But Cole (2003) highlights an interesting difference between the two words by examining the meaning from the Greek language. The word 'authority' comes from 'Exousia' which Cole (2003) states as "having the *right* to do something" – such as a policeman's uniform giving him authority to take into custody a person who has disobeyed the law. The word 'power' comes from the Greek word 'Dunamis' which implies "having the *ability* to do something" e.g. a prison officer having the ability to lock up or release a prisoner. In NH1, the nurse manager had the authority but my ability, or skill in palliative care, had undermined that authority. When authority for whatever reason is weak in an organisation, not recognising the power of 'expert skill' in an area where staff are looking to be re-skilled is very dangerous. As Cole (2003) points out: 'to have authority without power is degrading. To have power without authority is dangerous' (p.14). The nurse manager in NH1 had turned to the authoritative power of the owners as my expert skill in palliative care unintentionally undermined her authority in the team.

This difference between 'authority' and 'power' is important when considering action research. In the action research literature, 'power' is often addressed (Winter & Munn-Giddings 2001; Reason & Bradbury 2001). However, accommodating the importance of the hierarchical 'authority' is rarely mentioned. In dealing with change especially when one does not have authority because of doing action research in another organisation as an 'outsider', power issues are potentially heightened.

This hierarchical, authoritative power was not just present in the study nursing homes.[49] Quite by chance when I was with some staff nurses on the ward at the Hospice they were talking about patients for transfer to a local nursing home. The conversation diverted to one of the nurses speaking about how she nearly applied for a nurse manager's job in a nursing home. However,

---

[49] The authority/power issue in NH2 was more removed because of the larger organisation; however, it became an issue, though not with the action research directly; it was responsible for the nurse manager's decision to hand in her resignation during the study.

> *'... "the power of the proprietors was too overwhelming." She had felt she would never get the appropriate funding from management to keep staff up to date as well as keep the proprietors happy. She therefore never took the job."'* [Fieldnotes, 24.01.2001]

As I reflected more deeply over all of this I remembered that when we had first discussed the possibility of doing the action research in NH1, the nurse manager had been worried in case taking part in the study was acknowledging that they, as management, did not know how to care for dying residents and their family.

> *'We walked through into the proprietor's office and started the meeting. Both the matron of [NH1] and their other nursing home were present. I felt that [the nurse manager of NH1] was rather timid to begin with in the meeting especially in front of one of the owners which I found interesting since she had been working with them in their previous home for over 15 years. They had owned NH1 for 18 months but were concerned what the staff and families would think about them bringing in someone to help develop their end-of-life care. Long discussion over this.' [Fieldnotes, 11.05.2000]*

I had naively underestimated the importance of this fieldnote at the time. Clearly my skill was exaggerating an underlying concern. Unfortunately, I never got the opportunity to seek the nurse manager's viewpoint or to share these thoughts as I felt the situation remained too fragile.

By complete coincidence a few weeks later at NH1, I was examining one of the deceased resident's notes that had been collated and filed away with the notes from the previous management. I noticed a further clue to the difficulties I had experienced. As I examined the documentation provided by the previous nursing home owners and nurse manager, I realised from the care plans that they had worked from a person-centred approach. Some of the resentment that had grown up amongst the staff could have been as a result of the radical management change to the current task-orientated organisation of care with staff having less responsibility. I had then arrived using an action research approach, along with the principles of palliative care, both of which mirror the same values of a person-centred approach that clearly staff appreciated. Unfortunately it had the result of my being identified by management on the opposite side of the rift and try as I might to bridge the rift, without the regularity of management meetings, the rift was too wide. In my fieldnotes however there was clearly still some hope.

> *'The question is where do I go from here? Do I just continue the reflection and teaching or do we try and develop the following that has been discussed recently: i) the small, trained nurse group to help strengthen the nurse manager/staff relationship AND/OR ii) auditing the notes with [the nurse manager]. If I do ii) is there a problem with joining 'the power' set? However, I don't feel suggesting i) on its own is a good idea as [the nurse manager] would find it too difficult. However, if I use ii) as a way of sharing out the working, with [the nurse manager] pulling the notes and with me doing an outline... that may help to do something together. Watch this space!' [Fieldnotes, 22.02.2001]*

In the end, the traumatic experience over trying to discuss power issues confirmed to me that any further negativity in any additional in-depth work in NH1 was likely to have the same effect. Also, many of the original staff so supportive of the study had decided to move on. By the time I left NH1, there were only five of the original staff remaining. The work that we had done together was 'walking out the door' albeit to other nursing homes in many cases. I had tried my best to alert the management of NH1 but the dialogue had closed. I left NH1 as originally planned after one year.

6.7.2 Anticipating dying as an important part of ensuring quality end-of-life care

Brazil et al. (2004) raise the issue of recognising death as a significant event. However, the authors concentrate on the importance of recognising the grief experienced by staff and residents in the home *after* the event rather than recognising and anticipating the importance of dying itself. A second major theme, alongside the theme of 'death and dying being peripheral to nursing home care' (see section 5.4.1), that I was observing was the lack of formal attention to decision-making around the end-of-life and the resulting lack of anticipation of the dying process. As a result of the CLGs, staff were beginning to be more aware of recognising dying in their reflections and learning about the dying process. However, anticipating problems implicit in the dying process was still a problem. For example, staff were often chasing prescriptions from 'out of hour' doctors rather than anticipating symptoms as part of the dying process and having the medications already available. This was an added strain on nursing home staff who were already under pressure when a resident was dying.

> *'I asked whether the Fentanyl patches had been ordered - unfortunately they hadn't. If there had been anticipation of this happening by the nurse manager and the staff nurse on Wednesday when the GP discussed the Fentanyl, this would not be happening now – on a Friday afternoon at 4.30pm when the GP was not around! The nurse manager offered to phone the chemists to see re Fentanyl patches and the staff nurse left to speak to the GP re a prescription.'* *[Fieldnotes,03.11.2000]*

Situations such as this happened in both nursing homes. How much this was a denial of the situation and how much it was a lack of organisation or education was difficult to say but it occurred frequently. NH1 had a better record of anticipating that a resident might be dying which in part was due to the efficiency of the nurse manager and the fact that the GP not only visited weekly but was also interested in the care of older people. Even so, drugs were still not prescribed in anticipation of the last days and often it was not until the death was imminent that dying was in fact recognised. There were many entries in my fieldnotes that captured the frustration of numerous trips to various pharmacies. I realised the difficulty staff were facing: to be able to discern when a resident was deteriorating and would 'bounce back', and when a resident's deterioration would continue into the dying process. The dwindling dying trajectory (Lynn & Adamson 2003) made it hard for some staff to know what would be the actual outcome.

Instead of the dying process being a known event and one that was planned for, it was haphazard. However, this was not just because of the dwindling dying trajectory. It could be as arbitrary as to who was on duty as to whether the resident's deterioration would be acknowledged as dying, or left for staff on the next shift to decide. Many care assistants caring for the residents had little healthcare experience let alone knowledge about palliative care. Staff themselves in NH2a had raised this issue as a concern during the CLGs (see section 6.4.3).

It took an entry on the evaluation questionnaire sent to staff in NH2a following the nurse manager handing in her notice, to bring to my notice the importance of anticipating dying within the nursing home setting. One of the staff nurses had highlighted the importance of needing to anticipate the necessary care prior to a resident's dying in the nursing homes. Working part-time, this staff nurse knew the difficulties of a lack of anticipation and continuity in the care. She commented:

> *'It was useful to reflect and learn from experiences. [However] I feel that a pre-plan of action would be more beneficial in conjunction with a de-briefing session………I am very aware of forward planning rather than waiting until the event is upon us. Especially in respect of analgesia and other symptom controlling agents. To try and avoid 'crisis management' of symptoms near to death and avoid distress to resident and family.' [N1, NH2a: evaluation questionnaire].*

This staff nurse was suggesting the usefulness of a formal plan of care to guide high quality end-of-life care as a potential innovation within the nursing home. It seemed a most appropriate way of compensating for the staff's lack of theoretical knowledge in relation to end-of-life care. This staff nurse had realised that if care was not anticipated, dying residents suffered, whether because of a lack of medication, care assistants not being prepared that a resident was dying, or family not being present. It seemed this nurse was requesting some formal way of helping to guide the care being given to residents in the process of dying. She spoke with me directly about her idea and together we decided that I would go and search the literature to find out whether any such tool had already been produced. Ellershaw et al. (1997) had published their seminal work on developing the Liverpool Care Pathway for the Dying. It appeared to fit well with what the staff nurse was suggesting needed to be addressed, namely the importance of diagnosing dying. There was no doubt that a tool such as a care pathway for the dying had the potential of both guiding end-of-life care and anticipating the dying process, and aiding continuity of care in the complex and unstable mix of part-time and agency staff.

Developing palliative care knowledge alongside staff leaving and new staff arriving, especially in NH1, had been difficult. The CLGs had been important for individual learning about end-of-life care, but because of the poor retention of staff, the individual knowledge staff were gaining from the CLGs was not remaining in the nursing home. A care pathway could be a tool *within* the nursing home system that would be a permanent addition to enhancing end-of-life care. It would be a tool that would require a diagnosis of dying and insist on a greater multi-disciplinary involvement at the end-of-life with the GP being formally instructed on the need for prescriptions to ease any suffering a resident might be experiencing. The tool would also guide a holistic emphasis to end-of-life care. John Ellershaw's Liverpool Care Pathway for the Dying (Ellershaw et al. 2001; Ellershaw & Wilkinson) had been created to guide the care of the dying in hospital. It became a template that a core team in NH2b adapted for use in nursing homes. How the care pathway was adapted and implemented in NH2b continues this action research study into the next chapter.

6.8 CONCLUSION

This chapter has described the analysis of ten CLG sessions held in NH1 and NH2a as a way of developing end-of-life care knowledge amongst nursing home staff. Results show how the CLG sessions facilitated different ways of gaining knowledge through: staff being didactically taught within a session; staff gaining deeper understanding with the strengthening of their values about end-of-life care; and staff during the sessions beginning to challenge not only each other but also myself about end-of-life care. The sessions also provided an opportunity for staff to feel supported and valued. The regularity of a CLG following the death of a resident helped to open up communication around death and dying and assisted communication for staff across the nursing homes. Topics about end-of-life care that staff chose to raise as issues or difficulties were inductively generated from practice. A majority of staff found the groups very informative and supportive.

The chapter concluded with a reflexive discussion. Firstly, it highlighted the importance of a democratic impulse in action research (Meyer 2000) and how the clinical skill of an action researcher can be a threat to management when developing practice in nursing homes. The importance of regular monthly meetings was emphasized. Secondly, a further theme in the development of end-of-life care in nursing homes emerged: namely, the significance of anticipating dying within the nursing home setting.

The next chapter describes how the suggestion from the staff nurse within NH2a about the importance of planning the care in the last few days of life led to the action research being taken forward. An integrated care pathway for the last days of life adapted from the Liverpool Care Pathway for the Dying (Ellershaw et al. 2001) became an innovative tool used by nursing home staff to help anticipate and guide the care *before* a resident died.

CHAPTER 7

FACILITATING CHANGE THROUGH THE INTRODUCTION OF AN 'INTEGRATED CARE PATHWAY'

Up to this point in the study, I was learning a considerable amount from reflecting on the process of doing action research as well as some of the difficulties of developing high quality end-of-life practice in NH1 and NH2a. The importance of reflecting on one's action and the action of others, and then considering how that action might be done differently in the future makes reflection on action more than navel gazing (Freshwater & Rolfe 2001). Such a process had helped me realise the value of organised dialogue with management while undertaking critical action research in order to enable greater democracy and sharing of power. It had also highlighted the lack of a learning culture and the lack of a person-centred approach to care (Saunders 1987; Kitwood 1997) that appeared important for both residents and their families and the staff. As a result I sought a second nursing home (NH2a) that practised care from a more person-centred approach. However, because of the closed communication culture surrounding death and dying in these nursing homes, the staff in NH2a and I were realising that the care culture still lacked any systematic anticipation of the dying process before a resident died.

This chapter describes the introduction of an integrated care pathway for the last days of life (ICP) as an action to develop high quality end-of-life care. The ICP became complementary to the collaborative learning groups (CLGs) described in the previous chapter. However, before this action took place, a change in the nurse management of NH2 became instrumental in guiding this particular path of the action research cycle.

A change in nurse manager at NH2

After being involved with the study for nine months in NH2, the nurse manager announced to the staff that she would be leaving. All the staff, including myself, were very disappointed; staff had enjoyed the personal approach that this nurse manager gave to the residents and to themselves. Although tempted to leave myself, I decided to stay. It felt important to experience the upheaval for staff when a respected nurse manager leaves[50]. I also believed it was important to build on the current work and the relationships that had been forged across all staff groups. Both care assistants and trained nurses had done exchange visits between the hospice and the nursing home. One part-time nurse had enrolled in a new course[51] at the hospice; this staff nurse gradually became an important 'insider' for the action research in the nursing home. Her comment on the evaluation questionnaire (see Chapter 6 – section 6.7.2), sent out in anticipation of staff leaving as a result of the nurse manager's decision to hand in her notice, was key to the next action cycle. She was also fundamental to guiding the research forward - highlighting the need to anticipate care in the last few days of life.

NH2 split into NH2a and NH2b

A few weeks after the appointment of the new nurse manager to NH2 things were very different. Many nurses and care assistants *had* left – some as a result of the nurse manager's leaving and some as a result of the new management style imposed. Things were very different and the nursing home felt like a different place. NH2 split into NH2a and the now new NH2b. The new nurse manager did not manage from a person-centred orientation like the previous nurse manager (NH2a) but from an individualised nursing

---

[50] By the time the study finished NH2 had had 4 new nurse managers within a five-year period.

[51] A 'Palliative Care for the Elderly' course had recently been written by a team of us (representatives from local nursing homes – including the nurse manager of NH2a – and lecturers from the Hospice and the local university) and approved by the NHS Education for Scotland (NES). As of 2004 the course is now in its third year with over 50% of students coming from the nursing home sector.

approach (see section 5.2.1) where she was less involved with the clinical care. She appreciated the importance of a nursing focus rather than the medical model of task-orientated care. However, practice was *nursing*-centred and advantages for the nursing home over-rode those for the resident (Titchen 2000). One example of this was when a resident from the nursing home was transferred to a local long-stay hospital 'for reassessment' because she was seen as demanding excessive attention. There was no intention that once transferred the resident would return to the nursing home.

Despite the different way of managing care and the major changes in staffing, the new nurse manager was interested in promoting quality end-of-life care. She supported the action research study and enthusiastically talked about it during interviews with people applying to come to work at the nursing home. The staff nurse, whose idea was to develop a tool to anticipate the care needs of a dying resident, and I went together to the new nurse manager to share our ideas. We shared with the nurse manager the work of Ellershaw et al. (1997; 2001) on an integrated care pathway document for the dying. The nurse manager had a particular interest in accountability and audit. The idea of a tool that would not only help to anticipate the care for a dying resident but also help to audit that care was very attractive to this nurse manager and coincided with the care model from which she worked. The fact that this was the first nursing home in Scotland to be interested in implementing such a tool also appealed.

However, how would things stand once I left NH2b? I was conscious that we needed to develop care in such a way that those within the nursing home would take more responsibility in leading the change this time. The tool to help anticipate care in the last days of life had been the staff nurse's idea; the idea had arisen inductively from practice. It was important that they should lead this from the start. The nurse manager formed a small core group to adapt the Liverpool Care Pathway (Ellershaw et al. 2001) specifically for the nursing home, and to educate other staff within NH2b. The nurse manager wanted me to help her run the core group and take responsibility for adapting the actual documentation. There was greater ownership of this action cycle compared to the CLGs in NH1 andNH2a. As a result it was hoped that the actual culture towards end-of-life care in NH2b would be influenced, and any development sustained after the study finished.

7.1 INTEGRATED CARE PATHWAYS

Integrated care pathways (ICPs) are one approach to integrating standards and clinical guidelines within a multi-professional framework for quality assurance (Kitchiner et al. 1996; Wilson 1998). By recording the process of care around a set of standards compiled by experts in any given field, the ICP can be used to audit care against high quality standards. New initiatives such as ICPs or multi-disciplinary pathways of care have been gaining popularity in the evaluation of health care, although the successful implementation of a pathway is resource intensive (Mirando et al. 2005; Rees et al. 2004). Care pathways act as guides to treatment and aid the documentation of a patient's progress. They also provide a structure on which to assess both quality and cost of care. ICPs have been used as a way to manage financial aspects of care and audit its quality since the mid-1980s in the USA and Australia, with growing interest in the UK and Europe (Currie & Harvey 1997).

In the 1980s, Karen Zander, a nurse educationalist, adapted the idea of TQM (Total Quality Management) in order to manage the care of patients in a more dynamic way (Zander 1992; Overill 2003). In her use of care pathways, known then as CareMaps (case management plans), Zander (1992) advocates the need for greater integration between the differing professionals involved in a patient's journey through the hospital system. *'The documents become minimum action protocols and at the same time define and reinforce patient-centred care'* (Zander 1992: 314).

Although similar to the 'setting of standards' so widely used in nursing in the UK during the 1980s, integrated care pathways fulfil a much wider remit than just setting standards and doing audit. At their best, care pathways regularly monitor the actual *process* of care based on evidence/guidelines for a specific patient/client group. They integrate care at a multi/inter-disciplinary level. The care pathway becomes all or part of the clinical record, documenting the care given and facilitating the evaluation of outcomes for quality improvement (Riley 1998).

Overill (1998) lists over a dozen aspects on the NHS agenda where integrated care pathways are relevant, such as: organisational change, education, empowerment, efficiency, and risk management. Care pathways have been used in a multitude of different healthcare situations (Currie & Harvey 1997) but only recently have they been adopted in palliative care (Ellershaw & Wilkinson 2003).

In the UK, Ellershaw et al. (1997; 2001) were the first to introduce the idea of an integrated care pathway to the field of specialist palliative care in response to an increasingly outcome-based culture in healthcare. Palliative care is a complex field of care; the emphasis is on both a close multi-disciplinary working and the holistic care of patient and family. A multi-disciplinary steering group met to identify key outcomes/goals of palliative care by reviewing literature and patient documentation, and through multi-disciplinary discussion. The integrated care pathway for the dying developed by this steering group is known as 'The Liverpool Care Pathway for the Dying (LCP)' (Ellershaw & Wilkinson 2003). It encompasses goals focused on four key areas:

- identifying patients who were dying and making a 'diagnosis' of dying
- an initial holistic assessment
- ongoing four-hourly and twelve-hourly assessments
- care of relatives after a death

The process of care within the LCP is time-specific with goals to be achieved at specific intervals. Differing goals mean that a certain standard is achieved in the care of individual patients and their families. Any deviation from this standard is immediately recorded as a 'variance'. Variances themselves can be audited so that continuous quality improvement is dynamically achieved alongside identification of areas that may require education. The LCP was seen both as a tool to improve the care of dying patients and also a tool to empower those working in generalist care settings (Kinder & Ellershaw 2003).

Not everyone is an advocate of implementing care pathways. Kelly (2003) is concerned that the LCP may routinise the very individual process of dying. He advocates that the '*dying process should be left as unstructured and as far removed from any checklist as possible*' [p.39]. This is appropriate if all those working with the dying are trained and specifically motivated, such as in oncology wards and hospices. However, it will be argued later in the thesis that such a checklist could be helpful in non-specialist palliative care areas, for example nursing homes, where deaths do not occur regularly every week, the majority of staff are untrained and accountability is important. The use of 'variances' in the document also challenges staff to mobilise appropriate care. When a goal is not achieved and is at variance with established practice then a reason why the goal is not achieved and a statement as to what is to be done are required. This not only encourages critical action but also can personalise care towards individual choice.

Although formal models may be in danger of simplifying what is often a complex situation, where there is a lack of expert knowledge simplifying a complex situation can be helpful. Caring for a dying resident and his/her family is a complex area of care, especially within the nursing home setting where many care staff have received no palliative care education, there are few trained nurses, and there is inadequate medical support (Jacobs 2003). With a nursing home system that is not reasonably prepared to cope with an increasing number of deaths, an integrated care pathway, as a tool to highlight the importance of the last days of life, seemed reasonable.

7.2 DEVELOPING THE INTEGRATED CARE PATHWAY

Many issues about end-of-life care had been identified during the exploratory phase in the nursing homes in this study. It had seemed a complex task to tackle all the issues raised individually. The collaborative learning groups (CLGs) had been a tool by which experience-based learning about death and dying had been generated. However, I was conscious that as staff decided to leave the nursing home, the knowledge was 'walking out the door' with them. The integrated care pathway document was possibly a tool that could act as a more permanent means, within the rehabilitative nursing home culture, to promote end-of-life care: a document in which knowledge and guidance on end-of-life care would remain in the nursing home. Some of the staff and I began to see other reasons, other than knowledge walking out the door, whereby introducing the care pathway documentation might help to facilitate development of more appropriate end-of-life care in the nursing home. Box 7.1 highlights these reasons, and a fuller discussion of each reason now follows.

Box 7.1 Reasons for developing an ICP for dying residents in NH2

As a tool to:

- promote knowledge & practice of high quality end-of-life care to be incorporated as part of the nursing home system
- monitor & document care being given in the last days of life
- increase communication with the families of those residents who are dying when there might be a tendency to avoid this
- improve the *holistic* care given to dying residents and their families
- help staff anticipate care in the last days of life
- enhance greater multi-disciplinary working in diagnosing dying
- increase staff awareness of the process of dying
- empower nursing home staff in caring for dying residents and their families
- aid the facilitation of staff education

7.2.1 To promote knowledge and the practice of high quality end-of-life care

Action research is part of a new research paradigm that draws on a wide continuum of philosophies/theories to underpin different strategies (see Chapter 3). I began to see more clearly that developing practice about palliative care was not just about developing knowledge in the field and supporting staff as they cared for dying residents. It was also vital to see how the context affected such development. The staff nurse's idea about a tool to anticipate dying appeared 'to fit' with thoughts that I had had about the complexity of the nursing home system.

I had begun to be challenged by a systems theory (Checkland 1999) approach in which to frame these soft, ill-structured problems. Could a tool such as an Integrated Care Pathway (ICP) help to encourage a systematic approach to holistic care of dying residents within a system that is renowned as a 'Cinderella service'; where financial resources continue to be restricted, and where low morale and high turnover of staff/managers abound both in the UK and in the USA and Canada (Redfern et al. 2002; Kayser-Jones 2002; Brazil et al. 2004)? Could such a tool help increase staff confidence in end-of-life care within the generalist setting of a nursing home?

I had been encouraged by the commitment of staff to their dying residents and the eagerness of staff in both nursing homes to develop their knowledge about end-of-life care. Nonetheless, staff had found recognising dying and anticipating the needs of dying residents difficult. There was confusion about whose role it was to recognise dying. The ICP could be a tool for not only categorising and auditing the different elements of *holistic* end-of-life care in one document, but also for formalising care of the dying in the nursing home in a very practical way.

7.2.2 To monitor and document care being given in the last days of life

The systems used for documenting care in most acute care facilities have been found to be counter-productive with differing disciplines holding their own notes and little opportunity of sharing information (Hotchkiss 1997). It is not so different within the nursing home setting where often, care assistants have little access to information about the residents they are looking after. Although in NH2a there was a system for care assistants to be present at the 'handover', in NH1 and NH2b care assistants did not formally report back or record the routine care they gave to a resident who was dying. Instead, the nurse in charge would comment on the overall care given, despite not giving that care, and would write up the care plan. Not only would the ICP involve care assistants more in end-of-life care; it would also encourage the recording and reporting of 4-hourly goals (aspects such as restlessness, agitation, pain, respiratory secretions etc.) that were not being achieved. By monitoring the actual care given at a specific time, greater accountability would be achieved and care staff would be affirmed in their involvement with care given. The ICP documentation would encourage care assistants to be responsible for reporting 'unachieved' goals and challenge nurses to make sure that unachieved goals were acted upon. Working more closely together in this way would enable problems during the dying process to be systematically identified and addressed.

In an increasingly litigious society it is argued that using ICP documentation might reduce risks of litigation around end-of-life care (Hotchkiss 1997). Not only is appropriate evidence-based care inherent within the ICP but the care being given is also discussed across the disciplines and recorded in one document.

7.2.3 To increase communication with families of residents who are dying

The initial assessment of the ICP (as well as the on-going 12 hourly assessments) highlights the goal of communication with resident and family, and creates an opportunity for staff to talk openly about the last few days of life, if for some reason such communication has not already been taken place. During the exploratory phase in both nursing homes, the discussion with families about dying was often very limited and generally avoided.

> *MrG* *I realised that he was dying actually.....they never actually said but you know in conversations...you don't actually like...the word is not actually used because it was a matter of how long he was just going to last. It was pretty clear that it wasn't going to be very long. [Relative interview, NH2a: 17.04.01]*

Families often knew from observation when a resident was dying, but there was little 'open' communication. Communicating about dying within the nursing home setting is seen as difficult. A lack of recognition of the importance of the last days of life for the relatives and, more importantly, for the resident can trivialize dying (McCue 1995). The ICP documentation, being kept in the room of the resident who is dying, is then available for families to read.

7.2.4 To improve the holistic care given to dying residents and their families

The physical care of older people in both study nursing homes was superb, especially when a resident was dying. However, other aspects of holistic care were often lacking – as has already been cited in relation to communication about death and dying. Although ICPs are often seen as 'task orientated care plans detailing essential steps in the care of patients with a specific clinical problem and describe the patient's expected clinical course' (Campbell et al. 1998: 133), a care pathway for the dying is underpinned by a palliative care philosophy that includes goals for an holistic approach to the psycho-social and spiritual needs of a person who is dying. Before considering the ICP documentation, most young care assistants and even nurses in the nursing homes found it difficult to attend to religious and spiritual need. Staff had received no training in the psychosocial and spiritual aspects of care. An awareness of spirituality and the need for spiritual care was one aspect of care that was obviously lacking during the time spent in the nursing homes.

> *'Having bought some plants at the nursing home Fayre I then stood to chat to one of the residents who approached the table that I was standing by... Hesitatingly because of her difficulty in speaking and bringing the words to mind she told me, "I was just looking at some very sophisticated 'tapes' [I realised she meant the CDs on the other side of the table we were standing at.] ...and the first one I picked up was a 'Funeral March!' The lady screwed up her face at me as if to emphasize the reality of her fate.' [Fieldnotes NH2a, 12th May, 2001]*

Residents may not talk about death and dying much; however it is on their minds. Although both NH1 and NH2 had a regular Sunday service in the home, there was little evidence of any other religious or spiritual care. There was informal spiritual support through friends visiting and if a resident requested to go to church then arrangements were made. However, it seemed to me as though staff in the nursing homes were too busy to be able to attend to the spiritual needs of a dying resident and her/his family. Never had I heard it reported that a minister/spiritual adviser had been asked to visit a resident or attend to the religious rituals many older people and/or their families appreciate in the last days of life. It was not that it was unimportant in the minds of the staff but because there was no system, it was not addressed amidst the myriad of things to attend to.

7.2.5 To increase staff awareness of the process of dying

The process of dying was often ill understood by the majority of staff in the nursing homes. In NH2 during one of the CLGs there had been open discussion as to whether a resident had just been deteriorating or was dying (see section 6.4.3). There was both a genuine lack of recognition of the dying process and a lack of acknowledgement that a resident might be dying; some staff preferred to think a resident would 'bounce back'. Because of this, dying was peripheral to care in the nursing homes and on occasions symptoms such as respiratory secretions went untreated because of a lack of knowledge of what could be done.

The fact that dying was peripheral to the focus of care in both NH1 and NH2a had become an important finding of the study. It was hoped that by commencing an ICP there would be more open communication about dying, since an active discussion involving nurse, care assistants, family, GP and, where possible, the resident would now assist in 'diagnosing dying'. However, nursing staff in particular would need to take greater responsibility in this important work within the nursing home setting. With the decision made to commence the ICP documentation, staff would be monitoring goals during the last few days of life and thus become more aware of the actual process of dying. Increasing this awareness would help staff to be more knowledgeable about, and therefore less afraid of, death and dying.

7.2.6 To enhance greater multi-disciplinary working in diagnosing dying

Multidisciplinary working, pioneered by Dame Cicely Saunders in the 1960s, is a hallmark of specialist palliative care (Saunders 1987). Although it is increasingly adopted within the NHS, independent nursing homes are quite isolated from any regular multidisciplinary input and more importantly from medical care and advice (Glendinning et al. 2002). A local GP did visit NH1 every week to see residents, as a majority of the residents were registered with the practice; however, this was not the case in NH2b where a number of different GP practices were involved and all except one GP visited 'on request'. The common view held by nursing home managers in England, although not their GP colleagues, is that having several GP practices attend a nursing home and visiting 'on request' poses no problem (Jacobs 2003). However, this lack of organisational structure for medical advice makes planning medical input in the last days of life very precarious.

In the absence of any firm relationship with GPs, and a variety of opinions about end-of-life care, the ICP documentation encourages discussion and planning around evidence-based practice. This increased discussion between the nurse and the GP builds the professional relationship, increasing mutual trust and respect. End-of-life decision-making then becomes more coordinated, and marks the importance of the last few days of life.

7.2.7 To adopt a ‘guide’ for staff to anticipate care during the last days of life

Anticipating care during the last few days of life can reduce the unnecessary extra stress of not being prepared. On a considerable number of occasions during the study, staff had not anticipated certain medication that a resident then required during the dying process (see section 5.2.5, and section 6.7.2). The extra workload of trying to obtain medicines, especially during the evening or the night, was considerable. Using the ICP documentation, ‘prn’ medication would be prescribed by the GP in advance of any symptoms that might occur during the last days; this would prevent added stress for staff during the dying period in trying to get drugs ‘out of hours’.

Local palliative care guidelines, with particular advice on the last days of life, have been written (Lothian Palliative Care Guidelines 2000). However, in the study nursing homes, these guidelines were either not to be seen or were situated on a shelf in the office but not consulted. An integrated care pathway for the dying would contain set guidance for the day-to-day care; in addition, local specialist palliative care guidance on agitation, respiratory secretions, pain etc. would be included in the documentation. With all this information being kept in the resident’s room during the last days of life, up to date guidance would be accessible at any point in the dying process.

7.2.8 To empower nursing home staff

Ellershaw & Coackley (2002) report evidence of practical benefits as a result of using the Liverpool Care Pathway documentation, such as: acquisition of necessary skills in the last days of life; and empowerment of staff working within generalist settings. Untrained care assistants carried out the majority of care given to residents dying in the study nursing homes. Even though many of the care assistants were untrained, but not unskilled, there was considerable evidence that some did not know how much to 'intrude' on a resident's care in the last days of life if the family were present. Care assistants found it difficult to go into a room to 'turn' a dying resident if the family were present (see section 5.3.2). The ICP documentation would help to ease this pressure, giving permission and confidence for staff to carry out appropriate care and observation; it had the potential to increase accountability in the staff's work by requiring certain goals to be completed at regular time intervals.

7.2.9 To aid the facilitation of staff education

Nursing homes are known for having difficulties of recruitment and retention (Redfern et al. 2002; Deutschmann 2001) and the study nursing homes were no exception. The increasing knowledge that staff gained through the collaborative learning groups was walking out the door. A further benefit of using the ICP as documentation to aid end-of-life care would be the ability of motivated staff to learn directly from information contained within its pages (Hotchkiss 1997; Ellershaw & Coackley 2002). The ICP documentation would become a system for keeping palliative care knowledge within the home, and also prompt the education of new staff.

7.3 'ACTIONING' THE ICP

Currie & Harvey (1997) stress the importance of leadership, education and facilitation in their comprehensive discussion on the origins and use of care pathways. Attempts were made to make sure these aspects framed this next action cycle.

7.3.1 Leadership and the 'core' ICP action group

A number of short meetings were held with the nurse manager of NH2b. I had learnt the importance of not only working with the horizontal structure of staff caring for residents at the nursing home but also involving the hierarchical structure of management. The nurse manager was adamant that she saw herself as having 'devolved power' to do anything that she thought was appropriate in the nursing home; however, she reassured me that she would keep top management informed on the progress of developing and piloting the ICP. With the nurse manager playing an active role, a core group was formed to lead the project. The core group was 'handpicked' by the nurse manager, with each person having a strong interest in the care of dying residents. The group that was chosen consisted of eight people: care staff as well as nurses; the nurse manager as well as professionals from outside the nursing home (see Box 7.2). The nurse manager of NH2b chaired the meetings at the beginning; however, when she was not present, it fell to me to act as chair.

Box 7.2: Core group involved with leading the ICP project

Staff from within NH2b:

- the nurse manager;
- a full-time nurse (RMN);
- a part-time nurse (RN –'key insider);
- a young care assistant (recently done an exchange at the hospice).

Professionals from outside NH2b:

- a GP (medical responsibility for just over a third of residents);
- a nurse manager from another nursing home;
- a nurse from the national care home regulatory body (The Care Commission);
- myself.

The role of the group was to examine current end-of-life care practice in the nursing home and decide together what needed changing. The format and number of meetings was based on recent work done on developing care pathways by Kathryn de Luc (2001a; 2001b). Meetings were held fortnightly and lasted strictly an hour. Each meeting covered a certain aspect of the ICP development process. We had no intention to 'reinvent the wheel'; but rather, to draw on what was useful about the Liverpool Care Pathway for the Dying (LCP) 'Beacon Project' and how this might be adapted to NH2b's situation. One of the important acts in developing a care pathway locally is to identify what currently happens in the process of caring in any given situation, whether that be a surgical intervention or, as in this situation, caring for someone in the last days of life. Going through such a process with practitioners and management helps to identify aspects of care that might be missing from current practice. Ideas from the Lothian University Hospitals ICP for the last days of life (Farrer - personal communication), being developed locally for patients dying in hospital, were also available. After each meeting, topics that had been discussed, the action agreed, and who was to complete the action, were documented on an 'action sheet' [see Appendix 9] and circulated to everyone in the group. The initial meetings were not held in the nursing home because it was felt there would be interruptions; however, after a couple of meetings the group met in the nursing home as it meant less time away from the workplace. Attendance was reasonable considering the pressure on both GP and care home staff time; however, only at three of the eight meetings was everyone present. The GP and the care commission representative were the two group members most often not in attendance. The nurse manager and the care assistant missed two of the meetings.

7.3.2 Facilitation

The facilitation process commenced at the beginning of this project, with the core group meeting together and the nurse manager taking an active part in leading the meetings. Time was spent highlighting current end-of-life care being given to residents in the nursing home and what care the group thought required to be changed and/or needed to be added. The group then examined the Liverpool ICP template for nursing homes word by word. The following adaptations were undertaken.

i) Adaptation of the Liverpool Care Pathway (LCP)

The front sheet of the LCP was adapted to include clearly stated aims of the document. If this was going to be a document that would be beside the bed of each dying resident, the group felt it was important that the aims should be clearly stated, namely:

- to continue to provide person-centred/holistic care and support to the dying resident – bringing physical, mental, emotional and spiritual comfort
- to provide support and care to relatives/friends of the dying resident
- to provide instruction/support to staff so that they felt confident in the care of dying residents, helping staff to enhance a kind, thoughtful and professional attitude to death

The core group was adamant that care assistants should be more specifically involved in monitoring the four-hourly process of care (part of the ongoing care/problems) alongside a nurse, as and when appropriate. In the Liverpool template it was the nurse who documented achievement of the four-hourly goals and the doctor who documented the twelve-hourly goals. The group however wanted to give responsibility to the care assistant for the four-hourly care. It is often the care assistant who has got to know the resident the best over the months/years that the resident has been there (Flaherty 2001). The nurse would be responsible for 'actioning' any four-hourly goals that the care assistant reported as 'not achieved' and for achieving the twelve-hourly care goals.

Other changes within the process of care involved adding 'comfort measures' such as a fan, rearranging the room to ease nursing the resident, and retaining the importance of regular turning to prevent stiffness. The documenting of the twelve-hourly goals by the doctor was impractical within the nursing home context because of the GPs' increasing burden of work within the community setting (Jacobs 2003). Much more responsibility is given to the nurse within nursing homes. Nurses in these homes are increasingly the counterparts of the junior house doctors of the long-stay wards of the 1980s, and need to be aware of this expectation of them.

One considerable difference between the hospital context and that of a nursing home is the period leading up to making a 'diagnosis of dying'. Within the hospital setting, there is often an emphasis on tests, and on monitoring the patient with the decision not to continue the monitoring once a diagnosis of dying has been made. Within the nursing home, previous observations such as would be the norm within the hospital setting such as TPR and B/P are rarely taken. In the nursing home there is therefore a period where observations need to be taken in order to assess the seriousness of the situation especially because there is less of a medical presence immediately available. However, continuing with TPR and B/P as an observation following a collaborative diagnosis that the resident is dying would be inappropriate and perhaps seen as striving to keep the person alive.

The core group wanted to use different coloured paper for the various sections of the ICP documentation (see Appendix 11); this had been used in the Lothian University Hospitals ICP for the last days of life (personal communication). This made what could have been seen as a lengthy document more 'user-friendly' to the practice situation. The whole ICP documentation was put together in a plastic folder where 48-hour care sheets could be easily added as necessary. No formal printing of the ICP was carried out in order that further changes to the documentation could be made following suggestions by staff involved in using it in the nursing home.

ii) Deciding guidelines to be included in the ICP

The core group also highlighted areas requiring further work, in the form of protocols and guidelines to be included in the document. In this way a number of the group became facilitators for the further work. The care assistant in the group, with the help of the nurse manager, wrote a 'last office' procedure to help new staff know what bodily preparations needed to be done once a resident had died; and another care assistant had suggested having a special container in which to store the necessary equipment for the last act of care. The RMN nurse took responsibility for compiling a bereavement booklet to be given to relatives of residents dying in the nursing home, containing information about what to do after the death. A further protocol was written, explaining the procedure when a resident's body was to be removed from the nursing home.

The staff nurse whose idea it was to find a tool to anticipate necessary end-of-life care became the main advocate for the care pathway document and naturally became the 'insider' promoting its use and giving the necessary education for new staff.

7.3.3 Education

Many care staff and trained nurses in NH2b were already very interested in what the ICP core-group was involved in. Members of the group had chatted to fellow care assistants and this had the effect of making the rest of the staff feel included in the process. The nurse manager was particularly willing to make sure that the necessary education was done well. Because of nursing home pressures and the extra work for Christmas, the nurse manager decided to delay staff education. On reflection, because of the 'gap' that ensued, it was realised that some of the buzz and excitement about the venture dissipated. However this time was used to approach the six GP practices visiting the nursing home. I had thought it best that the nurse manager wrote to the different GP practices but she felt that it would have more effect if I wrote with the hospice notepaper. A positive response came from two out of five GP practices and a further practice wanted the group to attend one of their planned monthly meetings in order to explain the documentation. Those GPs who attended were extremely supportive and interested in taking part.

During the first week in January 2003, all staff were asked to attend one of the ICP education workgroups being held daily after the afternoon report. A 'values clarification' exercise (RCN 2002) was undertaken at the beginning of the workgroup to help staff think through together important aspects about caring for residents who were dying. This was followed by education on the ICP documentation, with those who had been on the ICP development team each leading a small group. The education was framed by a scenario-type case study (see Appendix 12) that each carer worked through, in order to feel more familiar with the documentation. The scenario had been specifically developed for the workgroups by one of the senior nurses. Everyone, including both day staff and night staff, took part, except for one care assistant.

7.4 EVALUATING THE EFFECTIVENESS OF THE ICP

Despite the wide use of care pathways and their formal recognition by the Department of Health as a tool for clinical governance, there are few evaluation studies of their effectiveness (de Luc 2000). It was important to evaluate what changes had taken place in NH2b as a result of implementing the ICP documentation. This evaluation has two sections: the changes in the care given to residents that occurred as a result of implementing the ICP documentation; and data on what staff thought about the ICP documentation itself.

7.4.1 Changes in care following the introduction of the ICP

During the adaptation of the ICP documentation and *prior* to its introduction, an audit of the notes of five residents who had most recently died in NH2b was carried out using a 'Base Review' audit sheet (see Appendix 10) supplied by the Liverpool Care Pathway group (Murphy 2000) [52]. The review sheet includes seven sections: 'demographic and diagnosis details', 'comfort measures', 'psychological/insight issues', 'religious/spiritual needs', 'communication with family/others/primary health care team', 'ongoing assessments', and 'care after death'. The five 'base review' audit sheets were then examined against data of completed ICPs.

---

[52] Documentation may already have been influenced because of the previous year's involvement.

The pre-ICP audit data is likely to have been biased in favour of palliative care because of the work with staff in NH2a in the year prior to the ICP implementation (NH2b). Staff had started to address issues that had come up in the CLGs i.e. pain assessment/management, understanding the dying process, the appropriate prescribing of palliative care drugs in the last days, and encouraging more 'open communication'. This may account for some aspects of care being done quite well in the pre-ICP audit data.

i) Improved attention to spiritual care

Nonetheless, one major difference in the documentation of care given to residents during the last days of life following the use of the ICP documentation relates to spiritual care. Whereas prior to the introduction of the ICP there was no evidence of religious/spiritual needs being assessed or addressed, in the audit of the post implementation of ICP documentation this was one area where staff had to ask families about their or the resident's wishes in order to complete this particular goal of the ICP. The documentation brought spiritual care to the staff's attention alongside giving staff permission to enquire rather than leaving it to the impulse of the staff on duty at that time. As a result of using the ICP documentation, three out of four relatives were asked about their spiritual needs and requested a minister to visit and so it was arranged.

ii) Difficulties of communicating with residents about dying

When examining communication about dying to families and the resident, there was evidence in the pre-ICP notes of three out of five relatives being spoken to about the care for the last days. All four relatives of those residents who died following the introduction of the ICP documentation had been fully informed about the condition of the resident, with the word 'dying' being used and the plan of care fully discussed. In the ICP documentation there was also clear documentation on when and how families could be contacted, so there was no confusion for staff in the middle of the night as to whether or not relatives wanted to be called. All telephone numbers were clearly and easily visible. Although dying was now being talked about openly with relatives, information on recording the 'insight about dying' for the resident was not so complete. In 50% of the ICPs used, this goal was not achieved. Nurses found it difficult to achieve this goal and staff felt less sure as to whether a resident should be told he was dying. More help was needed to deal with the anxiety nurses feel in talking about dying. Talking about dying remains one of the most difficult aspects of end-of-life care for any health professional.

iii) More appropriate prescribing

In examining the results in relation to aspects of symptom control and the giving of appropriate medication, not only were pain, nausea and vomiting, and agitation being *regularly* assessed every four hours but 'prn' medication was now being prescribed and given when appropriate. Non-essential medication had been discontinued in two out of the five base review notes compared to three out of the four residents who died following the implementation of the ICP; and, 'prn' medication had been prescribed in three out of five case notes prior to the study, contrasting with all four of those residents where the ICP documentation was used.

These data represent small shifts being made in the holistic care being given to residents in NH2b. Obviously the small numbers limit any fuller interpretation and a study using similar comparisons across a number of nursing homes introducing the ICP documentation would be useful.

Although all the staff had received the education regarding the ICP documentation, not all the staff had the opportunity to use it. A final evaluation specific to the implementation and use of the ICP documentation was undertaken and is described in the next section.

7.4.2 Staff views about the ICP and its implementation

In addition to the documentation audit, staff views about the pathway and its implementation were sought. Unstructured interviews were carried out with trained nurses (3), nurse manager (1), GP (1) and a relative (1). The relative and one of the nurses being interviewed for the first time were asked to give written consent; the others agreed informally. All interviews, except one telephone interview, were taped and interviewees were asked for permission to use the interviews as data. The recorded interviews lasted between 25 and 40 minutes. Questions varied but were based on a critical incident technique (Redfern & Norman 1999) to elicit what people had found useful and what was difficult about using the ICP tool. Interviewees were encouraged to talk about situations in which staff felt the ICP had improved care and the potential obstacles to its sustained use in NH2b (See Appendix 13a). An anonymous evaluation questionnaire (see Appendix 13b) with six 'open' questions was also sent to six staff who had used the documentation and were not available for interview. Four questionnaires were returned and the comments were typed up onto one sheet for ease of analysis. All interviews (6) were listened to two or three times and notes were made. Some sections of the interviews that specifically pertained to points useful for the evaluation were transcribed. Thematic analysis was undertaken within the core categories of what had been useful about the ICP documentation and its use, and what had been the negative aspects about the ICP and its implementation.

The majority of people felt that the development and introduction of the ICP had gone well. One person stated that they felt the study had improved morale and recruitment of staff to the nursing home. Two new staff had come to work at NH2b specifically because they were interested in palliative care and had been informed about the study at interview. The nurse manager said she felt it had been a huge success. One questionnaire was returned with one-phrase/one-word answers to each of the questions. However, the other questionnaires indicated that considerable time had been spent in thinking and commenting on the use of the tool.

7.4.3 Usefulness of the ICP

i) Acted as a reminder

Every person contributing to the evaluation commented in some way or other that the ICP acted as a good reminder about the care to be given. Some mentioned it was useful as a 'checklist', others said it gave 'guidance'. This was especially useful to those, even nurses, who may be unsure of what to do during the process of dying. Many people commented that having the information as a reminder, even though many were already giving good care, meant that both nurses and care assistants were more confident.

> *"Now that we've got this [ICP] in place it's all there for you. That's the way I feel professionally, Jo."* *[NN3, evaluation interview]*
>
> *"It's all there, they know what they're doing. It's like a checklist. And the senior care assistants also have got that wee bit more empowerment..."* *[N1, evaluation interview]*

Whilst most of the trained and untrained care assistants found the ICP useful as a guide on aspects of caring for a dying resident and their family, the GP found the formal pain/anxiety guidelines printed at the back of the ICP helped act as a 'crib-sheet'.

> *"GPs do not look after many dying patients within a year so regular experience in palliative care is limited". [GP interview]*

Although nursing homes are facing an increasing number of deaths, GPs still do not get the same exposure to death and dying as nursing home staff because of the number of different GP practices involved. Also, many GPs see their primary task to 'make better' and not necessarily care for the dying. The fact that the ICP was a document that was in use in the room alongside the dying resident meant that the GP had ready access to guidance on pain or agitation, for example, should he/she require it.

ii) Inclusiveness and continuity of care

One of the groups of people who can sometimes be excluded from in-depth communication when a resident is dying is the family. When a nursing home does not have the regularity of a weekly visit from the GP, there is considerable apprehension among nursing home staff about what should or should not be said about a resident's deterioration and what should be said by whom. This was raised as an issue in a number of the focus groups in the exploratory phase in both NH1 and NH2. The ICP appeared to give staff confidence to sit down and speak with relatives about the situation. One staff nurse felt the ICP documentation enabled the family to feel part of the decision-making process and be more involved in the care.

> *"...I don't see a problem with the relatives looking at it [ICP] because it lets them get involved with what is happening..."[N1, evaluation interview]]*

This same nurse insisted that one of the important things about the ICP documentation was that it was in the resident's room. Where to keep the ICP documentation had been debated at length in the 'core group' development meetings, with some members feeling the ICP documentation should be in the resident's room while others worried about confidentiality. Having the documentation in the resident's room also appeared to aid communication, especially with the family, because they were included more.

> *"I would much rather that I could observe what they were doing...I thought it was wonderful...I appreciated very much being shown that [ICP]...they treated me as an equal and I appreciated that". [Relative, evaluation interview]*

This inclusiveness also appeared to extend to the important role that the ICP had when agency staff were working in the home. The ICP was ensuring an evidence-based standard of care when regular staff were absent, as well as continuity between different shifts.

iii) Clarifying a complex situation

Caring for dying people, even the very old at the end-of-life who might be seen as having had a 'good innings', can be difficult for untrained care assistants. As a student nurse, I had been taught and supported in the care of the dying, but now with an increasing number of older people dying in independent nursing homes, many young, untrained care assistants are ill prepared, with little or no teaching on the care of the dying. Care assistants build up strong relationships with the residents in nursing homes and many come to be seen as 'family' (Moss et al. 2003). A couple of people stated that the ICP helped them to be more objective at a time when it was difficult to cope emotionally.

> *"The main benefit I found was it helps clarify what can be a difficult and emotive series of events into a rational operation" [CA1, evaluation questionnaire]*

For them to have some clarification of their role in end-of-care through the ICP documentation appeared to ease stress: a place where policies such as 'last offices' could be easily accessed. The GP interviewed suggested that the tool helped him focus more appropriately on what needed to be done in the last days of life.

The one relative who was interviewed reiterated this sense of making a complex situation more ordered.

> *"The thoroughness ...the total dedication to detail and to duty...I thought my mother's passing was so dignified because of this [ICP]. And I thought everything had been thought about. And it was all very calm - there was no racing or rushing around. All the nurses seemed to know exactly what they were doing and everybody fitted in like a jigsaw". [Relative, evaluation interview]*

There was an underlying sense that the documentation highlighted the importance of dying; that it was something that was not trivialised, even though many of the residents in the nursing home were very old.

iv) Recognising dying & the importance of holistic care

The nurse in a nursing home has a very important role in organising and coordinating the care for residents who are dying. However, prior to the ICP implementation, some staff were unsure about taking such responsibility. The documentation empowered staff to take control of the situation and gave a focus to the different aspects of care. There was better communication with families as well as an improvement in communication among staff. Because of the ICP documentation people now knew when a resident was dying and it was being talked about. Any symptoms that might occur were being more confidently acted upon.

> *"I think it is absolutely essential to have a diagnosis of dying so that we can treat symptoms…and I think we are treating the symptoms much better than we were. I think we are much more prepared when someone is going to die. We are much more prepared." [N1, evaluation interview]*

If there had been an inclination in the past to 'hope' that a resident was only deteriorating rather than dying (see section 6.4.3), the documentation highlighted the latter. One carer commented that this might be one of the negative aspects of the ICP, with the appearance of the documentation heralding that the person is dying. This very comment suggests that some care assistants, given the chance, would prefer not to acknowledge the situation. This then blocks appropriate communication with, and support of, relatives. However, other care assistants welcomed the greater open communication that the ICP provided:

> *"The ICP lays down a good structure to the care of the dying resident. Following the ICP ensures all aspects of care are covered, ensures solid communication between staff and offers guidance where required." [CA4, evaluation questionnaire]*

One of the nurses who had been working at the nursing home for two years felt that a deeper commitment to care for the dying had developed since the ICP documentation project. Two staff stated that the ICP ensured that all aspects of care (not just the physical) were covered.

> *"I just think it made you look at things a lot deeper. For me myself personally, it made me feel that I was doing every last little thing I could possibly do. Maybe I felt like that before but now I felt you had guidelines to sit down and look at and put you through the process of it. It makes you look much deeper into it …making sure everything is as it should be." [NN2, evaluation interview]*

v) Easier to use than first thought

Most people evaluating the ICP had never heard of care pathways before. At the beginning of its introduction, a number of staff admitted it all sounded rather complex. Others had been apprehensive as to whether its introduction was likely to cause a lot of extra work. Still others had felt that it was just another way of documenting what they did already. However, staff found that actually using the documentation was less complex than many had anticipated. What they thought was going to cause more work did not occur and, as already stated, it clarified what could be a complex situation.

> *"Initially I thought…it was like the ICP was going to be more work….but that was because everybody else had a rather negative attitude… 'An ICP – what's this now!'. But also I think things are introduced and then put to the side…but hopefully this [ICP] will continue".* *[NN.2, evaluation interview]*

> *"I wasn't very impressed when I first saw it. I was quite daunted by it but now that you've used it…yeh, it's actually quite satisfying…knowing that the resident has had everything done." [NN.3, evaluation interview]*

The way the ICP documentation was introduced – the process of its adaptation, the education and then the final facilitation of its introduction – were an important part of the process to ease its transition.

One aspect of the ICP documentation that is important, but which is difficult to grasp, is the reporting of a deviation from the goals to be achieved. This 'variance' reporting, as it is called in the document, plays a major part in care pathway documentation. Considerable attention was made to teaching about 'variances' in the training sessions. The 'variance' form was well used and staff did not find its use daunting. Some felt variances helped to clarify their thoughts prior to phoning the GP, and aided the critical thinking on end-of-life care. Even the GP commented specifically on how the 'variance' challenged him to reassess his use of analgesics.

> *"The greatest impact the ICP has had on me has been the variance…and the need to reassess my usage of Fentanyl and other analgesics…" [GP, evaluation interview]*

There was a sense therefore that the ICP provided useful documentation for differing groups of people caring for a dying resident, including the family:

> *"I found it extremely useful at all levels……from qualified staff - we had guidelines; the care assistants it gave them more confidence in that they knew that they were doing the 4 hourly checks – it gave them a lot more confidence; from the families' point of view, you had something in your hand to explain what was going to happen…[N.1, evaluation interview]*

7.4.4 Difficulties of introducing/using the ICP

i) Time to set up

Whereas using the ICP documentation was not seen to be more hard work, the actual 'setting up' each ICP was time consuming. Putting someone on an ICP meant that more time was spent not only with the GP but also in explaining to the family what was happening. Families found this opportunity to ask questions really helpful but it was very new to the staff. This extra time and commitment required to complete the initial assessment when a resident was being started on an ICP did prove a difficulty. It was often the same staff nurse each time who actually instigated the commencement of the ICP documentation.

> *"Not a lot of other people have suggested that we use the ICP……the night staff are not awfully happy about it unless it has been set up. It is the actual setting up, speaking with the GP…there's quite a lot of the staff feel that if someone else sets it up for them they are happy to use it". [N.1, evaluation interview]*

This nurse was very comfortable with issues about death and dying. It had been her idea in the first place to have a tool to anticipate the care in the last days of life, so it was natural for her to be involved in 'setting up' ICPs and using her skill as an 'expert' insider. It was a concern that if for any reason this nurse was away for a lengthy period (e.g. sickness), staff might not have the confidence to commence the documentation. With only four ICPs being completed, it was not possible for all staff to get this experience. One of the other difficulties in setting up the ICP was encouraging the GPs to spend the time going through the first assessment. The GP who had been on the initial 'core group' was very supportive, but other GPs who had not attended the training, although invited, were irritated at the time it took to complete the documentation even though it was only about 10 minutes. Often they were happy to talk things through but sometimes did not get round to completing and signing the documentation. The danger here is that the documentation is seen as 'nursing' documentation and the concept of an 'integrated' care pathway is lost.

ii) Using the documentation

Recording aspects of care so regularly was a change to the routine care of a resident who was dying especially for care assistants.

> *"The volume of factors seems a bit overwhelming" [CA3, evaluation questionnaire]*

A number of people, both trained and untrained care assistants, mentioned difficulty with the wording in the document despite changes already having been made from the original document (e.g. 'excessive secretions'; 'opioid toxicity').

> *"From a clinically un-qualified point of view, the layout and some of the terminology seemed slight alien to begin with." [CA4, evaluation questionnaire]*

When the meaning of the words was explained to care assistants, there was no further problem. However, with the high use of agency staff within nursing homes, this point was taken seriously and as the nurse manager of NH2b was now leaving, I made the changes to the final ICP working document. Further work would need to be carried out in other nursing homes to ensure wider comment and correction.

iii) The need for training

The need for continual training on the ICP documentation for new staff was important. By the time I was evaluating the ICP in NH2b, there were only four nurses on day duty out of the original ten who were still working in the home when I first started. No care assistants who had initially been working on day shifts remained. I was concerned about how staff would continue to educate new members when few of the original staff remained. Such turnover of staff in a nursing home can prevent new learning taking place, as so much effort goes into maintaining stability in the home. However, there was evidence that the use of ICP documentation was being explained to new staff. In some situations those doing the explaining were the care assistants themselves:

> *"...At the end of the shift after I had written my notes [the care assistant] came to see how I had got on with the ICP and to her horror she found that the carer who had washed the lady had not filled in his section. Instead of the annoyance that I had expected, she started to tell me what a great opportunity this was for her to tell this carer about the ICP and about how useful it is." [Agency nurse – e-mail contact to me]*

Education of staff is important if the use of ICPs is to be sustained in unstable contexts. However, because of the lack of a learning culture within nursing homes, education can be perceived as 'extra work' rather than part of the job required in caring for residents. The ICP documentation was a useful document whereby practical teaching could be done alongside practice. With new staff arriving and the use of agency staff in NH2b, there was a constant need to keep explaining the ICP documentation during the day-to-day care of a resident who was dying. It was affirming to hear that this was occurring. In a study to introduce an ICP into a hospital environment, Fowell et al. (2002) comment that 'ward-based learning, even on a one-to-one basis, was the most effective training' (p.61).

It is acknowledged, as in Section 6.5.1, that generalisation cannot be made from the small numbers in this evaluation and it would be important to repeat the project in a larger number of nursing homes over a longer period of time.

7.4.5 Continuing to use the ICP documentation

As I prepared to leave NH2b[53], there was real eagerness among the staff at NH2b to see the continuation of the ICP documentation. Individual commitment to learning about and using the ICP documentation, despite the continual pressure of work within the home, was impressive. They had all taken responsibility in different ways and wanted to see its use in the home continued.

> *"It will get used. Again it has not been introduced by one person... We need something like this. This has made [caring for the] dying a lot easier." [NN2, evaluation interview]*

Facilitating the implementation of the ICP by appointing a 'core group' with one particular 'key insider'[54] had enabled staff to take ownership of the project. Not only had this meant that the documentation and the focus on end-of-life care had become embedded in the nursing home culture; hopefully it would also mean that the implementation of the ICP would be sustained over time and that the ICP documentation would continue to help guide quality end-of-life care in the future:

> *"I am fully committed to the ICP and I will keep it going. I will fight for it at the end of the day. I don't think we will have to fight for it. This is established now at NH2b and it is up to us to make it work now." [N.1, evaluation interview]*

Making sure that this was not just an initiative for trained nurses in NH2b was very important. Involving care assistants had been a key part of the success of the ICP implementation. A year or so after I had left NH2b, a fellow PhD student, who knew about my work from the student PhD writing group at the university, happened to be doing an agency shift at NH2b without realising this nursing home was where my study had taken place. One of the residents on the floor where she was in charge was dying.

---

[53] There was yet another change in nurse manager. The nurse manager of NH2b handed in her notice after only 11 months as nurse manager, to go and live abroad. We had managed to successfully develop and pilot the ICP documentation but still further staff left. This time it felt appropriate that I should leave NH2b – I had been involved with staff in the nursing home now for just under 2 years.

[54] A further discussion on 'key insiders' and bringing about positive change in action research follows in the final section of this chapter.

The ICP documentation was in the resident's room and she then realised that she was in one of the study nursing homes. She was struck by the enthusiasm of one of the care assistants for its use. For my encouragement she posted me an e-mail. The following extract confirms the importance of the care assistants' role in such a project:

> *"....[the care assistant] talked at length about how much it means to her and her colleagues to be able to contribute to the care planning for this lady. She told me how important it is that the lady should have skin care, mouth care etc. and spoke with real authority about the importance of making the lady's remaining time comfortable and the role of the ICP in doing this. She showed a great deal of insight and excitement about the ICP and is certainly encouraging her colleagues to think along the same lines! ....These people love the tool and are telling complete strangers about it with great authority!"   [Agency nurse – e-mail extract]*

A final comment in the above e-mail read: *'Both you and the carer inspired me by showing me the possibilities of putting research into practice!!'* This highlights the importance of action research. The e-mail was sent to the new nurse manager for her encouragement.

7.5 REFLEXIVE DISCUSSION

In the reflexive discussions in the previous two chapters, two major themes relating to end-of-life care in nursing homes were discussed[55] alongside two out of the three significant aspects of action research highlighted by Meyer (2000), namely the importance of participation in action research (see section 5.4.2) and how such an approach needs to be underpinned by a democratic impulse (see section 6.7.1).

In the reflexive discussion of this final major action cycle chapter, the third significant aspect of action research is discussed, namely the capacity that action research has not only 'to influence practice positively but at the same time collect data to share with a wider audience' (Meyer 2000: 179). This section reflects on the 'seesaw' effect in

---

[55] These major themes related to:

- dying being peripheral to nursing home care;
- anticipating the needs of dying residents in order to achieve high quality end-of-life care.

bringing about change in some situations and then highlights how the ICP documentation, through the facilitative process used in its introduction to the nursing home, enabled staff to bring about change in the organisational culture of NH2b. Secondly, this section discusses how the process of the action research study highlighted issues intrinsic to the culture of the study nursing homes that adds to knowledge about the end-of-life care for older people in this setting. It details some of the differences between dying from cancer within a specialist palliative care setting such as a hospice and dying in a nursing home. It raises important issues to be addressed at an organisational and policy level if the inequality of end-of-life care for older people is not to be ignored.

7.5.1 Changing the organisational culture of nursing homes

The different developments that occurred around end-of-life care in each of the nursing homes were significant to those individuals taking part; but some developments had a greater impact on the culture of the nursing home than others. Whereas the CLGs had developed knowledge about end-of-life care in individual members of staff in NH1 and NH2a, it was the development of an integrated care pathway (ICP) for the last days of life in NH2b that appeared to have the greater impact on the both the culture and the routine monitoring and coordination of care in the nursing home.

The changes to end-of-life care that occurred in the different nursing homes were strongly influenced by the degree of how ready and willing the nurse manager and the management were to change (McCormack et al. 2001; Paton & McCalman 2000) and the relevance of the change initiative to staff within the context (Williamson 1992). I now reflect on three aspects in relation to change and influencing practice in this study.

Is 'volunteering' for an action research study enough in order to bring about change?

The staff in NH1 cared passionately about improving the actual care in the last days of life and it was not difficult to encourage this enthusiasm. However, my differing fieldnote entries reveal how 'up and down' the whole action research process felt, and my apprehension concerning the loss of interest in the study by those in management.

> *' [A letter from the Care Commission regarding the new palliative care category*[56] *that nursing homes can apply for] appears to have 'turned' the momentum of the research to one that is much more "collaborative". Because the original design/outline of the research was not in collaboration with the nursing homes, although they volunteered to take part, there has always been this feeling of them [nurse manager & the owners], and us [the staff and me]. Gradually I feel this is changing to a much more equal partnership. I think this may have come about because [one of the owners] now feels more in the driving seat.' [Fieldnotes, 06.11.2000]*
>
> *'As I write this I feel exasperated and feel that it is very likely nothing will change. The owners and nurse manager are very much in charge and that's that.' [Fieldnotes, 07.02.2001]*
>
> *'The owners and presumably the nurse manager feel I have overstepped my boundary following the formal feedback report. My remit in their eyes was to develop palliative care, not to start criticising the organization' vis-à--vis support of staff, task-orientated care versus person-centred approach to care'. [Fieldnotes, 22.02.2001]*
>
> *'The nurse manager went over and got the 'palliative care file' and proudly handed it to me saying nothing. I opened it and realised she had put an article into the folder. Again she appeared to value what we were doing.' [Fieldnotes, 12.04.2001]*

After I had been at NH1 for 5 months, a difficult, prolonged death of a 65-year old resident from cancer had affected many staff including management. The staff had managed very well and following the discussion at the CLG session, it was clear they were feeling good about what they had been able to achieve. However, one of the owners had a different impression. He had found it very difficult to cope with. Both owners had known the resident for many years and her slow deterioration and death had clearly affected the owners. Neither owner had any health care training but being in the nursing home every day continually reminded them about Mary's slow decline. This

---

[56] A 'palliative care' category was an additional category of care that nursing home owners could apply for to the national regulatory body for care homes (The Care Commission). During the study, the historic 'terminal care' category that some nursing homes on the boundary of the City had been given was discontinued. Nursing home managements were now being encouraged to apply for this new 'palliative care' category.

incident appeared to influence their thoughts about applying for the category of palliative care for their nursing home.

> *'The Taylors really feel now that they are wondering about the whole issue of "palliative care" category. Mr Taylor stated that all the staff were "very shocked" over Mary's death, and if that was how dying from cancer was then that they might think twice. I agreed it was a very difficult but unusual situation. I disagreed over how "shocked" the staff were. However, I am not sure a palliative care category is appropriate where the fundamental premise of palliative care, that of person-centred approach to care, is not acknowledged'. [Fieldnotes, 22.02.2001]*

One major incentive for volunteering to take part in the study the owners told me was their interest in accessing a category for palliative care in order to promote their business (see section 6.7.1). However, taking part in the study highlighted management's awkwardness with a more open policy towards death and dying. This had been apparent in the exploratory phase (see Section 5.4.1) and was always an underlying problem that was never really resolved despite some very important work being done with the staff. When the NHS Board announced that there was to be no separate palliative care category, both this and the managers' difficulty with the prolonged dying of the resident appeared to coincide with their losing interest in the study. Chenoweth & Kilstoff (2002) report a similar loss of interest with a number of managements when undertaking action research to reform care in aged care facilities in the USA.

In NH2a, the reason for volunteering to be part of the study was more focused on practice. The nurse manager in NH2a had had a bad experience when her father died in a care home; she wanted to make sure that no-one had to experience the same grief as she had. Because of this, she was more open about the need to communicate about death and dying. Another enhancing factor was the nurse manager's specific interest in person-centred care (Kitwood 1997). Person-centred care or 'patient focused care' as it is known within the hospice movement underpins a palliative care approach (Saunders 1987). This nurse manager's understanding of change management and the eagerness of both staff and management to develop practice around end-of-life care helped to ease the difficulties associated with change. The readiness to change, the emergence of a respected staff nurse passionate about end-of-life care who became an key insider (Titchen & Binnie 1993a) in NH2b, and the formation of a 'core' group in NH2b to take ownership of the ICP documentation, were significant factors that led staff to further develop high quality end-of-life care.

How important is a 'core' group or a key insider when bringing about change?

Staff and I, in NH1, had talked about forming a specific 'core' group as part of the change process but for many reasons this did not occur. Whether staff in NH1 were feeling vulnerable due to recent changes within the home and so wanted to 'stay together', or whether there was a sense that a small group might be rather exclusive in such a small nursing home were both plausible reasons. Although just before I left NH1 we had formed a small core group with the blessing of the owners, the group never materialized because within a few weeks every member of the core group decided to leave.

There is no doubt, however, that I was more experienced as an action researcher by the time I moved to NH2a and even more experienced in NH2b when the core group came together to develop the ICP documentation. In NH2b it was easier to form a 'core group' because of the flatter organisational structure and the tradition within the home of developing practice and devolving power to staff. The 'core group' was very committed and *owned* the task of adapting the ICP document, with the nurse manager inviting care professionals from outside the nursing home (GP, another nurse manger etc.) to take part. This gave further respectability and accountability when it came to asking members of the group to take on the responsibility for developing aspects of the ICP documentation e.g. the care assistant who took on the task of writing a procedure for doing 'last offices' or the staff nurse who created a bereavement booklet. Kitson et al. (1998) in their model of implementing evidence-based practice highlight the importance of good facilitation when changing practice. With such a committed core group facilitation was not difficult. The idea of facilitating others continued when members of the core group taught the rest of the nursing home staff about the ICP documentation prior to its implementation.

In NH2b, there was also a respected staff nurse experienced in end-of-life care who became a 'key insider'. In NH1 the nurse manager had found it difficult to devolve power to her trained nurses. The deputy matron (although only working 4 days a week) would have been an ideal 'key insider' but was not given the necessary support and acknowledgement. In NH2b the situation was different. The nurse who became the 'key insider' also had previous experience in palliative care; being part of the action research study gave her permission to be an appropriate facilitator within the nursing home to keep staff focused.

How much was practice positively influenced?

It is important to state that the CLGs developed in NH1 appeared to be the appropriate action for that context at that specific time. The nurse manager found change, especially change to documentation, extremely hard. Some attempt had been made by the deputy manager prior to NH1 being involved in the study and again by both of us during the study to speak with the nurse manager about a greater 'person-centredness' to both the care and the documentation generally, but this was declined. The idea of developing specific documentation to anticipate the last days of life (such as the ICP developed in NH2b) never came to our minds in NH1, although I had been conscious of differing aspects of end-of-life care that could be addressed. The action that emerged from discussions during the exploratory phase in NH1 at that point in time, which may well be relevant to other nursing homes, was the importance of supporting staff in their end-of-life care along with creating a learning culture. The CLGs that evolved were the vehicle for this to occur; however, as has already been discussed, much of the learning that took place 'walked out the door'.

In comparison, there is evidence that the ICP documentation which was developed in NH2b did positively influence not only individual practice but influenced how end-of-life care was practised. As a result of the ICP documentation there was more direct challenge to the closed communication culture around death and dying, improving knowledge about the dying process and challenging the nursing home system to anticipate the care involved in the last days of a resident's life.

7.5.2 Contribution to theory on end-of-life care

One of the main differences between action research and other research paradigms is its ability both to develop practice and at the same time contribute to a greater understanding of the subject being researched – in this case to the theory of end-of-life care. As I have reflected on the facilitation of the development of knowledge about end-of-life care within the nursing homes, I have become increasingly aware not only that the nursing home is a different context for dying compared to that of a hospice, but also the nature in which death occurs in the very old is different. With a greater emphasis in nursing homes on rehabilitation, whereby the focus of care is often around tasks (Froggatt 2000a), dying becomes peripheral to the focus of nursing home care. A comparison between dying in a specialist palliative care unit/hospice and dying in a nursing home is made in Table 7.3 overleaf, and a more detailed discussion follows.

Specialist palliative care/hospice units, which care for those people who die in 'mid' life[57] from cancer, are organised through a multi-disciplinary model of care that includes doctors, nurses, care assistants, pharmacists, physiotherapists, occupational therapists, and ward clerks caring for relatively small numbers of people. In contrast, nursing home residents, an increasing number of whom have several different pathologies including advanced dementia, are cared for by staff the majority of whom have little or no training even though residents could be described as having 'advanced, progressive, non-curable disease' (Doyle, Hanks & MacDonald 1993: 3) – a phrase that defines palliative medicine.

---

[57] With the increasing life expectancy, 'mid-life' is translated as those aged between 50-70 years of age. The 'very old' are people aged from 85 years and above.

Table 7.3: Differences between end-of-life care in hospices and nursing homes

Specialist palliative care/hospice	End-of-life care in the elderly dying/NHs
Focus on one disease process	Multiple disease pathologies – less than 10% cancer
Emphasis of dying in mid-life [50-70yrs] or younger when life seen as being 'cut short'	Natural ending of life [over 85 yrs], often understood by resident as being 'timely'
Clearer concept of 'prognosis' – short period of evident decline	Prolonged dwindling trajectory (Lynn & Adamson 2003); lengthier process of slow decline that often includes the phenomenon of 'bounce back'
Professional relationship between patient and staff; patients mostly dying within a 3-month period	Often closer/emotional relationship between resident and NH staff – especially when resident has lived in the home as long as a year or more
More support from family/friends who visit regularly	Less support from family/friends – friends have died and/or too frail to visit; NH staff seen as 'family' (Moss et al 2003)
Both patient and family often want life extended	Greater acceptance of life being at an end - speaking about wanting 'not to wake up in the morning'
Multi-disciplinary model of care – free, quick access to any health professional necessary	Nurses and care workers form major part of workforce; access to geriatricians, PAMS is fragmented; rarely use hospice for advice (Hockley et al 2004)
Education of all staff plays an important role in hospice work	Lack of a learning culture
More medical intervention seen as appropriate – 'dependent' dying	Less medical intervention during the dying phase – 'autonomous' dying
Patients rarely cognitively impaired	Greater percentage of residents have cognitive impairment
Most hospices registered as charities – legacies often left to hospice. No ethical conflict	Majority of NHs 'for profit'; residents pay towards care – selling their house in order to pay; rarely 'extra' money left to NHs. Ethical conflict of making money out of care for older people with cognitive impairment
Pro-active use of volunteers (supported/trained)	Volunteers rarely used
Majority of hospice units have strong fund-raising initiatives including charity shops	Some fund raising but limited to what can be done 'in-house' i.e. Spring Fairs, Christmas Raffles etc.
Dying is integral to the focus of care although there is a strong emphasis on patients 'living until they die'; underpinned by a 'person-centred/patient-focused' holistic approach to care	Greater emphasis on 'living' (Froggatt 2001); dying is peripheral to the focus of care; care often focused around tasks and 'getting the work done'

Just under a third of residents die each year in nursing homes in Scotland; however, the majority of nursing homes lack the multidisciplinary resource and staff lack training for quality end-of-life care. Residents in nursing homes stay considerably longer than the mean 13.1 days that patients stay within a hospice (Eve& Higginson 2000), staff have a longer time in which to form closer relationships of greater emotional depth with residents. This was very evident in NH1, NH2a and NH2b. This is in contrast to a more professional relationship commonly seen in hospices. This is not to say one is better, only that they are different.

The nursing home is often depicted as the resident's 'own home', and staff in the study nursing homes spoke about residents in terms of 'family'. Residents appeared to appreciate this and it has been documented that such a term reduces the sense of burden that a resident might experience when so dependent on someone to care for them (Moss et al. 2002). Hockey (1990) suggests that the intimate caring for residents found in nursing homes is unusual outside familial relationships. Staff members in nursing homes may feel they need to replace the function of the family (Katz et al. 2000). More recently Moss et al. (2003) identify the metaphor of 'family' in their research about dying in long-term facilities. They discuss the idea of an increased tension in caring for a dying resident who has been in a nursing home for many months/years; a tension between the *personal* experience for the caregiver who has come to know the resident as 'family', and the *work* experience of losing the care-giving tie. Because of this, it is argued that the impact of a death when caring for a dying resident in a nursing home is greater compared to that of hospice carers. Staff in nursing homes require more support, especially given the increasing number of deaths, and increasing dependency.

A striking difference and one that has already been extensively addressed in this thesis is the lack of a learning culture in nursing homes. Most nursing homes are isolated from NHS services and education (Katz & Peace 2003) but hospices, although often outside the NHS system, are very much seen as an extension of the NHS. Hospice philosophy is underpinned by a motivation to provide education not only for hospice staff but also for NHS staff. It is likely that, given their isolation from innovative practice, many nursing homes still manage care from a task or individual nursing care perspective rather than from a person-centred approach. A person-centred model, especially because of its alignment to palliative care, might be a more appropriate model for nursing homes.

Many older people in nursing homes have the opportunity to die a more natural death (see pages 165-166) than patients dying in mid-life from cancer. Within the nursing home there is less input from a multidisciplinary team compared to the hospice. This lack of a multidisciplinary presence in the study nursing homes may have given a greater degree of autonomy to the deaths of older people. For residents in the nursing homes, there was less dependence on the medical profession, despite their obvious dependency on care staff, and less use of complicated and expensive treatments when compared to the hospice. McCue (1995) discusses the loss of a will to live in older people as being a common cause for death. However, what I saw was something less negative. I saw a natural withdrawing from life, and in some cases, an unspoken readiness to die. Many patients and families cared for in hospice units see life as being 'cut short' and often want life prolonged; however, this was not the case for the very old in nursing homes who on several occasions openly admitted to me their wish to 'go to sleep one night and not wake up'.

The prolonged dwindling trajectory of the very old (Lynn & Adamson 2003), so specific to residents in nursing homes, made predicting the dying phase complex. The slow dwindling with the 'bounce back' phenomenon is not something associated with hospice care. Instead, in the hospice, the dying trajectory is most often a steady decline over a matter of months towards the dying phase rather than the 'ups and downs' over years with some older people in nursing homes.

Finally, as I worked alongside staff in the nursing homes, I realised there was a major difference in how hospices and nursing homes are funded. Although both are mostly funded outside the NHS, hospices have caught the imagination of the public who generously support fund-raising initiatives, volunteer to work at a hospice, and leave legacies in their wills for its work. The independent hospice requires this support in order to supplement finance from the government. The 'for profit' status of both small nursing homes and large nursing home organisations means that there is little volunteering from the public. For those independent nursing homes that survive on financial remuneration from the government only, there is often very little profit. Independent nursing homes carry out very important work in providing the major care for frail older people in the UK; however, their 'for profit' image of making money out of vulnerable older people can be perceived as inappropriate.

The differences identified above between the hospice context and that of nursing homes with regard to end-of-life care are not exhaustive. Nursing homes, however, need to emerge as places that can confidently fulfil their role in the end-of-life care of older people that is specific to their context. They need to become places where older people can die naturally at the end-of-life with the necessary support, and where staff have the expertise to enable them to do so.

7.6 CONCLUSION

This chapter has described how, as a result of the inspiration of one nurse in NH2b, a 'core group' of staff adapted the Liverpool Care Pathway for the Dying from its original use in the acute hospital setting, to make it a more appropriate tool to guide the care of older people dying in a nursing home. It has described the objectives behind implementing such a tool, which had been derived inductively through the process of the action research. It then discussed an evaluation of the ICP implementation and evidence that objectives were met.

Introducing a care pathway for the last days of life to NH2b enabled staff to be more confident when caring for dying residents. Making a 'diagnosis of dying' appeared to create a greater focus on end-of-life care when a resident was dying in the nursing home. There was a more holistic approach to the care of the dying and a greater 'openness' about the dying process. Relatives were more included in the process of dying, and using the ICP documentation helped to establish not only better communication with relatives but also better teamwork, inside the nursing home and amongst the wider multidisciplinary team. A limitation, however, was that, due to the small number of residents who died at the nursing home during the last three months of my stay in NH2b, there was limited opportunity to see the ICP documentation used.

The reflexive discussion highlighted specific issues around bringing about change in the nursing homes. It also highlighted not only the different dying trajectory of those dying in a nursing home but the difference in the context when compared to a hospice.

In the next chapter, I return to Habermas's *Theory of Communicative Action* to discuss the major action described in Chapter 6 (the collaborative learning groups) and the major action in this chapter (the introduction of the ICP) to highlight the importance of the lifeworld of staff and the system of the nursing home when developing high quality end-of-life care in this setting.

CHAPTER 8:

DISCUSSION

The point is not to claim credence for a view of critical action research by appeal to authority... It is to show that some central problems of contemporary social theory have clear resonances for our work as action researchers. Problems about the nature of practice, the relationship between theory and practice, the relationship between systems theory and theories of social action, tensions and interconnections between system and lifeworld, the relationship between the critique of the philosophy of the subject and the critique of the social macro-subject ... all these (and others) are highly relevant to a contemporary understanding of the potential and limitations of our theories and practices of action research.

Kemmis 2001, p. 101

In this chapter, I explore further the significance of the inductively derived actions, namely, the collaborative learning groups (CLGs – chapter 6) and the integrated care pathway (ICP – chapter 7). For this I draw on Habermas's *Theory of Communicative Action* (1984, 1987a) and highlight important aspects of Habermas's theory on modern society with particular attention to the equal importance of the *lifeworld* and the *system*. I then relate this first to the relevance of the CLGs in supporting the individual and collective *lifeworld* of staff and their caring for dying residents and their families; and then to the relevance of the ICP as a tool to enhance high quality end-of-life care within the nursing home *system* where, because of an emphasis on functional rehabilitation, end-of-life care is rarely openly acknowledged. I propose the relevance that the CLGs and the ICP documentation may have is in 'recoupling' the *lifeworld* and *system* in the systematic development of end-of-life care in nursing homes.

In section 8.2, I discuss new insights that I have gained through this study about the process of doing action research in the study nursing homes. For this, I draw further on Habermas's *Theory of Communicative Action* and the direct link that Kemmis (2001) makes between Habermas's theory and action research. I discuss some of the issues in relation to action research highlighted in the quote by Kemmis (2001) at the beginning of this chapter. Finally, I consider the theoretical implications of my discussion about my use of action research and prospects for further practice development.

8.1 AN INTERPRETATION OF THE TWO ACTIONS IN LIGHT OF HABERMAS'S 'THEORY OF COMMUNICATIVE ACTION'

As detailed in Chapter 3, Habermas's work is based within the Frankfurt School of critical theorists. Habermas's interest in democracy and the importance of dialogue and action in order to overcome difficulties within society is the basis of his *Theory of Communicative Action*[58]. In his theory, Habermas (1987a) conceptualises modern society as having two equal perspectives: the *system* in which we live and, the *lifeworld* of the people as an integral part of that system. For Habermas the *system* is portrayed as the economic system of capitalism. In his theory, the increasingly complex manner in which the capitalist state operates means that the *system* becomes increasingly autonomous, with potentially less and less human element within that system. Habermas (1987a) criticises Parsons' thesis on social systems where the *lifeworld* of people within the system is marginalized as part of a sub-system. Habermas (1987a) believes that the *lifeworld* is much more vital - more a symbolic space where personality and culture are experienced and reproduced (Porter 1998). Habermas states that by reducing the lifeworld to a sub-system, such a theory inadequately describes the ability that people have, in their social world, to understand and rationalise about complex issues. In his *Theory of Communicative Action*, Habermas argues for the importance of the *lifeworld* as having a value on a par with the *system.*

---

[58] For a general introduction to the *Theory of Communicative Action,* see Rasmussen (1990) and White (1988); for an understanding of Habermas's concepts of system and lifeworld, and the thesis of internal colonisation, see Fairtlough (1991). For an excellent overview of all perspectives of Habermas's critical theory, but in particular Habermas's *Theory of Communicative Action* and its significance to action research, read Kemmis (2001).

Drawing on Habermas's argument concerning the *lifeworld* and the *system*, I now pose an interpretation of the actions undertaken in this study. For this, I take as my starting point the world of nursing homes. It is within nursing homes that an increasing number of older people now die. However, as this study has shown, staff caring for these residents have had little or no teaching and education on death and dying, and receive little support. I discuss how the CLGs could be seen as supporting the individual and collective *lifeworld* of staff in end-of-life care and the subsequent influence to bring about change. I then turn to focus on the individual nursing home as a *system* in our modern society: a place that is being given increasing responsibility to care for frail older people but one that is often ill prepared to deliver quality end-of-life care.

8.1.1 Valuing the *lifeworld* of staff through the CLGs

Habermas (1987b) defines *lifeworld* in relation to his *Theory of Communicative Action* as:

> *'Considered as a resource, the lifeworld is divided in accord with the 'given' components of speech acts (that is, their propositional, illocutionary, and intentional components) into culture, society, and person. I call culture the store of knowledge from which those engaged in communicative action draw interpretations susceptible of consensus as they come to an understanding about something in the world. I call society (in the narrower sense of a component of the lifeworld) the legitimate orders from which those engaged in communicative action gather a solidarity, based on belonging to groups, as they enter into personal relationships with one another. Personality serves as a term of art for acquired competencies that render a subject capable of speech and action and hence able to participate in processes of mutual understanding in a given context and to maintain his own identify in the shifting contexts of interaction.'* (p.343)

From this explanation of the lifeworld, Habermas (1987b) identifies three structural components of the *lifeworld* through which individuals speak and relate to other human beings. These are: the skill of an individual to contribute to a shared appreciation of a situation; the collective identity whereby people get support from being part of a group; and the culture whereby an accumulation of knowledge has the potential of consensus to bring about change. A discussion now follows using these three structural components in relation to how the CLGs supported the *lifeworld* associated with end-of-life care.

Reference is made to the data of this study and the literature to support such an interpretation.

i) The process whereby the CLGs developed personal skill of staff in caring for dying residents

The CLGs enabled individual staff members to increase their understanding about end-of-life care and to gain support. They were a place where individual staff had opportunity to learn to reflect on the care given to a resident whom they had cared for; learning therefore was relevant to the individual and to his/her situation whether this was a nurse or a care assistant. This knowledge enabled individuals who came to the CLGs feel more comfortable with death and dying. The informality of the sessions meant that staff were not afraid to seek answers to their questions.

> *'I feel more confident and not so stressed. I know what is happening' [CA, NH1: evaluation questionnaire]*
>
> *'Most helpful to discuss any problems I may have experienced - also those of others. Also helpful with suggestions on varying aspects of end-of-life care which I can use in the future' [N2, NH1: evaluation questionnaire]*
>
> *'Since it is the first time I have cared for dying residents, I found it most helpful to know what was happening to them and the different stages. It also helped to be able to talk about it.' [CA, NH2a: evaluation questionnaire]*

Miskella & Avis (1998) note that rarely is the individual emotional cost of caring for dying residents addressed. The CLGs gave staff legitimated time, within the busy schedule of nursing home work, in which they could express their own thoughts and feelings about how it was to care for a dying resident. The CLGs gave opportunity for staff to come to terms with the loss of someone to whom, in most situations, they had grown very close, because they had cared for the person over many months, and in some cases, years.

The CLG sessions appeared particularly significant for the care assistants. The results of the evaluation of the CLGs revealed that all [nine] care assistants returning the evaluation questionnaire rated the helpfulness of the CLGs with a score between 6/10 and 10/10 (where 10/10 is 'very helpful') (see section 5.6). The CLGs provided a place where they could comfortably express individual opinions about end-of-life care and develop their own thoughts about death and dying. Staff appreciated being able to tell their story or share their feelings during the CLGs:

> *'Instead of bottling things up you were able to talk about it' [CA5, NH2a: evaluation questionnaire]*

A number of staff had been involved in the death of a loved one that they had not been able to adjust to (see Section 5.2.4). The stress of coping with dying, especially if a previous experience of death has not been dealt with, can adversely affect an individual and thus impact the lifeworld and a person's ability to interact with people who are dying. Copp (1997) advises that it is not possible for a person to be constantly reminded about death without that person having first considered their own mortality. Many of the staff had never had the opportunity to consider dying in light of their own mortality. The majority of care assistants had had little to no teaching about death and dying so the subject had never been opened up to them. The CLGs provided an opportunity where this emotional cost was legitimately recognised.

As staff shared their difficulties, they learnt from one another. Sometimes this was about the actual process of death and dying being explored. At other times it was about mutual support and realising that others felt the same.

> *'Being able to discuss events leading up to death and death itself. Realising that one is not alone with these feelings.' [CA3, NH1: evaluation questionnaire]*
>
> *'Very helpful to hear the views of other members of staff and to have a discussion with a co-ordinator present.' [N2, NH2a: evaluation questionnaire]*

Because of the number of part-time staff in both nursing homes, many staff did not feel they knew each other very well. The CLGs gave an opportunity for staff to meet together and in some cases even get to know who the night staff were. Getting to know each other aided a mutual understanding across different staff groups.

> *'A chance to open up for staff to each other, day staff including cleaners. Night staff – to get to know day staff even better – hopefully to the residents' benefit'. [N3, NH1: evaluation questionnaire]*

The CLGs were not only encouraging personal learning and skill by reflecting on their individual practice in order to inform end-of-life care, but they were also fulfilling a supportive role to individual staff after the resident had died. These two elements enabled staff to be more confident to speak about death and dying and the care that they, as individuals, wanted to be able to provide.

ii) The process whereby CLGs enhanced collective identity in end-of-life care

Personal relationships were being strengthened through the CLGs. Speaking openly about death and dying together enabled a deeper interaction between staff. The CLGs gave time and space for both trained and untrained staff to come together to share concerns and tease out problems about death and dying (see Section 6.4.3).

Prior to the study, there was no other time when staff would meet together as a group to discuss end-of-life care, other than informally during a coffee or tea break. In NH2a the handover report for all staff had been abandoned shortly after I started in order to save money. As a result, the trained nurse reported to the trained nurse coming on duty; and that nurse then went round the various care assistants to pass on any relevant information as she/he thought appropriate. In NH1, it was a traditional handover where the nurse manager gave all the information with little extra time given to discuss care or give extra support to staff. It could be argued, therefore, that the CLGs were fulfilling part of the role found in a holistic nursing handover[59] where staff would meet altogether to support each other and report back about the care of their individual patients.

Hopkinson (2002) has highlighted the importance that support and a sense of belonging to a group is for nurses caring for dying residents and their families. An unexpected finding of her research when researching end-of-life care in the acute hospital was that nurses being interviewed spoke about missing the nursing handover where 'the collaborative narrative of the handover allow[ed] for the containment and support necessary for nurses to deal with the often disturbing nature of their work' (p.170). This collaborative narrative had been happening in the nursing handovers when I first started in NH2a. However, without appropriate handovers in the study nursing homes, the CLGs were acting as a point of reference for the team to come together and collectively talk through issues surrounding the care given to dying residents.

But for some, learning to reflect *together* about practice was quite an alien concept.

> *'I feel guilty sitting in the group while there are 24 other residents to see to.' [NM, NH1: final group evaluation]*

For this nurse manager, who had been used to a traditional task-orientated approach to nursing care and education, it was difficult. Despite considerable evidence that she was a person who did reflect on her work, she found the sessions quite alien. Even though there were care assistants allocated to look after the residents during a CLG, she still found it hard to see staff 'sitting around' discussing the care of a resident who had died.

> *'...time was not being spent on the current residents whose needs were – at the time – greater.' [NM,NH1: evaluation questionnaire]*

---

[59] A holistic nursing handover (Odell 1996) is one where all staff caring for residents/patients will have an opportunity before going 'off-duty' to report back together about the people they have looked after. In this way, not only do staff get to learn through discussing together, but they also get an opportunity to leave behind difficult/stressful events by voicing their concerns. This is not possible with the current emphasis on tape-recorded handovers where the emphasis has been on saving money.

Nonetheless this nurse manager attended a majority of the sessions, which staff really appreciated. Although the nurse manager never led a CLG herself, she did allow the groups to continue once I left NH1. Staff were not only gaining confidence in their individual understanding of death and dying. Being part of such a group highlighted a collective identity amongst staff in raising the importance of end-of-life care as part of a team[60].

> *'It seems that a staff nurse appears more confident to speak her opinion when there are other staff nurses around such as in the CLGs. They are empowered by other nurses around and can give their opinion..'. [Fieldnotes, 21.01.2001]*

The voice of both nurses and care assistants in the team was being heard as a result of the CLGs. The increasing solidarity amongst staff about the importance of high quality end-of-life care enhanced teamwork as staff came to realise its relevance within the context of the nursing home. The sessions provided the nurse manager of NH2a with the opportunity to give collective supervision to her staff following a death, which again legitimised the importance of death and dying. As quoted in Chapter 6:

> *[The CLGs] gave a very valuable opportunity to the manager to hear first hand from a group of workers their thoughts and feelings on a death. It gave scope for reflection on practice and provided a safe environment for staff to make their views known. From this, future training/planning could be formulated. It also values staff which I feel is extremely important in this field of work.' [NM, final evaluation, NH2a]*

Miskella & Avis (1998) and Kayser-Jones et al. (2003) both report that a lack of supervision in caring for dying residents had a negative impact on staff, and Miskella & Avis (1998) reported it left care assistants feeling ill-equipped and lacking in confidence. Through the CLGs, recognition of their valuable contribution to dying residents was being highlighted.

---

[60] For care assistants to be given such an opportunity to discuss openly, and even influence future care by what they said, could be an important factor in staff turnover in nursing homes. Banaszak-Holl & Hines (1996) found that turnover amongst untrained care assistants was significantly reduced when they took part in interdisciplinary care plan meetings. Even though care assistants are 'untrained'; this does not mean they are 'unskilled'.

iii) The process whereby the CLGs were able to influence the nursing home culture surrounding end-of-life care

The lack of a learning culture generally in the nursing homes (see Section 5.3.2) was being addressed through the CLGs. Prior to the study, many staff, especially care assistants, saw the job of caring for older people in the nursing home as something that they came in and did, without necessarily thinking about learning from the experience of caring.

The CLGs provided an important opportunity, in a culture of 'getting the work done', for staff in the nursing home to stop and think. In the sessions, staff were being challenged, and challenging each other about the status quo of end-of-life care (see section 6.4.3). Staff in the CLG sessions were learning to critically discuss their previous actions in caring for the resident who had died. This was especially true when staff in both nursing homes talked about the difficulties of informing families after the unexpected death of a resident. Whereas many nurses were not used to informing relatives over the phone if a resident had died suddenly, and instead made some excuse to bring them up to the nursing home, this was now being more openly scrutinized. The sessions promoted mental stimulation. Many different issues were reflected upon and discussed (see Table 6.2). By learning about death and dying together, staff were better equipped the next time and often the stimulation was having an energising effect.

There has been much debate about 'burn out' in the care of older people in relation to the unending heaviness of the work. However, this argument is now challenged by Redfern et al. (2002) who characterise 'burn out' in the care of older people as being as much about 'rust out' and the lack of mental stimulation as it is about physical exhaustion. An important aspect of the CLGs was the stimulation that resulted from the discussions. Often after a CLG session, there was a buzz of interest amongst staff as they left the group to continue their work.

Care of the dying was now being seen as an important issue that had not been raised before in such a systematic way. For the first time, the CLGs were focusing on learning more about the taboo subject of death and dying. The closed communication culture was being challenged. Staff were feeling more supported. Staff were also being empowered not only to speak up about end-of-life care but also about other issues in the nursing home.

As a result of the CLGs in NH1 and NH2a, death and dying was becoming more of a focus of nursing home care as staff themselves felt more confident. End-of-life care in both nursing homes was being addressed on an on-going and regular basis every time a resident died in the nursing home. The CLGs were challenging the functional rehabilitative culture of nursing home care.

> *'There is great emphasis on motivating and stimulating those residents who are up and about but there are a number of residents who spend all their time in their rooms or in bed and I feel there could be much greater input here to try and improve their quality of life'. [P/T N, evaluation questionnaire NH2a]*

8.1.2 The ICP document as a tool for guiding high quality end-of-life care in the nursing home system

Just as modern society needs organisational and institutional structures (including roles and rules) in order to function as a system (Kemmis 2001), so also do nursing homes in relation to high quality end-of-life care. However, in the study nursing homes there was no such formal guidance. Staff had instructions in a procedure book about doing last offices, but there was no structure to the dying process in terms of who was responsible for aspects of care and making sure certain drugs and procedures were in place. In many ways this was not a surprise, as staff were not thinking actively about death and dying. The nursing home was not a hospice, which one might more readily associate with dying. Having no specific organisation for end-of-life care within the nursing home system meant that it was more difficult for staff and/or owners to create a culture of open communication about death and dying.

Maintaining an appropriate balance between a rehabilitative culture and end-of-life care is perhaps unique to nursing home work[61]. There is a potential conflict between the nursing home as a place where life is to be lived, and a place where death commonly occurs (Froggatt 2001a). Getting a right balance in nursing homes between the rehabilitation culture and appropriately preparing for death can be a challenge and one that those managers of nursing homes without a social or health care background may be reluctant to face. Recognising dying in older people is not easy and only recently has the dwindling dying trajectory of the very old (Lynn & Adamson 2003) been conceptualised in the literature. Often prediction concerning dying in nursing homes has been left to the GP. Increasingly in the UK, nurses within the nursing home setting are being encouraged to take more responsibility for the care of residents, as they and the care assistants are the ones who know the residents the best (RCP, RCN, BSG 2000). However, failure to recognise dying is a major barrier to quality end-of-life care (Brazil et al. 2004). In order for death and dying not to go unnoticed (see Section 5.4.3), it is important that nursing home staff have some guidance whereby quality end-of-life care is addressed.

i) Guidance for end-of-life care in nursing homes.

The ICP provided documentation that encouraged an open dialogue about end-of-life care within the functional rehabilitation culture of the nursing home system. Nurses, GPs, care assistants and family members were encouraged to meet together to discuss whether a resident might be dying and together plan appropriate care. In this way, dying was being more readily recognised. This strengthened the relationship between the GP and the nurse. With the introduction of the ICP documentation, nurses had more opportunity to be part of the decision-making process about death and dying and to be pro-active in addressing specific goals at the end-of-life (such as control of symptoms, good communication and the spiritual needs of resident/family – see Section 7.5.1).

---

[61] Comparing this to the emphasis on the care of the dying in a hospice, and the emphasis on cure within hospitals, one realises how unique the nursing home context is.

The ICP became an important tool within the nursing home *system* whereby the ICP documentation informed staff knowledge on the control of distressing symptoms and the holistic care of both resident and family. As highlighted in Chapter 6 (see Section 6.7.1), prior to the introduction of the ICP documentation, much of the end-of-life knowledge that staff gained through the CLGs, and through my working alongside dying residents, was disappearing when staff for whatever reason decided to leave the nursing home. The ICP documentation was a tool that was being used to help guide the care of a resident's last days of life that remained in the nursing home *system.* Care assistants as well as nurses found the ICP a very helpful document that worked at different levels of care. Care assistants were given the responsibility to assess any distress in the resident, while the nurse was required alongside the GP to address what needed to be done to ease suffering.

ii) Achieving goals and outcomes in end-of-life care

An essential part of a system functioning well is the attainment of set goals and targets (Kemmis 2001). In the nursing homes, prior to the ICP documentation, there were no set goals or targets to guide end-of-life care. Most staff just hoped for a peaceful death for their residents with little knowledge of how to achieve it. However, the various goals set out as part of the ICP documentation reminded staff of the differing aspects of holistic care to be achieved during the process of dying.

The ICP for the last days of life encouraged greater clarity when dealing with what those participating in this study saw as a complex situation (see section 7.5.3). It supported the nursing home *system* in this way and could be used to audit care in the future.

Travis et al. (2002) highlight that the 'management of the environment in which the resident is dying and the ongoing support for the family/resident relationship and the bereavement process requires an active rather than passive nursing role' (p.312). The very fact that the ICP document encouraged goals to be assessed every four hours emphasised the fact that there was something for the staff to actively participate in; and they were able to critically analyse situations, rather than just wait until a resident died. As part of the ICP documentation, the prescribing of PRN medication in anticipation of end-of-life symptoms such as agitation, pain or respiratory secretions meant that symptoms were actively anticipated, resulting in less chaos when getting hold of medication for a resident who was dying. The ICP encouraged an active role within the nursing home in caring for a dying resident and communicating with the family.

Although the ICP documentation appeared quite technical, giving a structure for end-of-life care that helped staff know what to do in anticipation of a resident's death, it also provided a much-valued occasion for staff, the GP and the resident/family to communicate. In this way, as part of a multi-disciplinary assessment, a formal opportunity was created in which staff and resident/family could decide how things should be taken forward to ensure dignity and control of symptoms at the end-of-life. The ICP documentation encouraged a more reliable way of organising care when a resident was dying and promoted a quality of end-of-life care based on research evidence (Ellershaw & Wilkinson 2003).

In having to achieve goals set out by the ICP documentation, staff put more critical thought into understanding why a resident's anxiety, for instance, was not being controlled, and what would be necessary in order for the symptom to be controlled. Staff began to be more independent of my advice and feel more confident. The nurses themselves were reporting 'why' a goal was not being achieved, which was making staff critically analyse the situation themselves, and they were learning by it. Both nurses' and care assistants' basic knowledge about end-of-life care was being challenged; for the nurse, information about aspects of end-of-life care that they might not be familiar with, such as anxiety, was readily accessible in the documentation; for the care assistants, because they were assessing goals such as the comfort of the resident and whether there was any distress, added responsibility was being given, to inform the nurse. Care assistants appreciated taking on this responsibility.

Using the ICP documentation not only provided guidance for better control of symptoms during the process of dying but also contributed to a more open communication culture. It could be argued that the ICP documentation was having a greater influence on the end-of-life culture in nursing homes than the CLGs. However, there were potential negative effects. Firstly, as reported in Chapter 6, one care assistant in particular reported that the introduction of the ICP made her feel that death was 'more in your face'. Secondly, the ICP documentation is only a tool, albeit a very good tool. The care being carried out and the continuity of using the ICP will both depend on the commitment of staff. In NH2b, staff were extremely committed to developing end-of-life care. The care of every resident who died was now being guided by the goals of high quality end-of-life care set by the ICP and carried out by committed staff who wanted to make a difference. Relationships were being strengthened between nurses and care assistants, and between nurses and GPs as respect and trust grew between them.

8.1.3 Recoupling of the *lifeworld* and the *system* in the development of end-of-life care

To recapitulate, Habermas's theory highlights the *lifeworld* as being of equal importance to the *system* of a society and not as a sub-system. For Habermas, a correct balance between the *lifeworld* and the *system* is very important to the functioning of a society (in the narrow sense). When the system becomes more dominant, and the human voice is lost, a tension occurs. Habermas (1984) calls this tension, this lack of balance between the lifeworld and the system the 'uncoupling of the lifeworld and the system'. In Habermas's thesis this uncoupling is triggered in politics by an increasing complexity of the system whereby responsibility for maintaining a society has been removed from 'individuals and small face-to-face social groups' (Kemmis 2001, p.96).

If nursing homes, as an important *system* in society, are now a major setting where older people die, and statistics in the UK (NCPC 2005; Scottish Executive 2003) appear to confirm this; and if such settings are to promote quality end-of-life care, then staff in nursing homes require appropriate support and practice development. Kemmis (2001) highlights that problems arise for staff 'when the personal, social and cultural processes that sustain the setting as a lifeworld collide with those processes that characterize the setting as a system' (p.94). The demand on the nursing home *system* over the last ten years to accommodate more dependent residents, and as a result an increasing number of deaths, has been enormous. There has been no intervention (such as an increase in staff ratios and appropriate practice development) to enable nursing home staff to cope. Coupled with poor recruitment and retention of staff, it is not surprising that nursing homes as a *system* are under strain and that staff morale is low (Redfern et al 2002). It could be argued, therefore, that because of the increasing complexity of the nursing, such a situation increases tension between the *lifeworld* of staff and the nursing home *system*. In reality it would appear from this action research study that staff feel inadequate to cope with their limited knowledge of end-of-life care amidst a culture of rehabilitation and closed communication about death and dying. As a result tension is inevitable.

This action research study has shed light on the inadequate practice development of high quality end-of-life care within nursing homes. The two inductively derived actions represent fundamental aspects that contribute to high quality end-of-life care in nursing homes: the CLGs acknowledge the importance of valuing the *lifeworld* of staff and of recognising both the emotional and intellectual needs that staff have in caring for dying residents and their families; the ICP documentation draws attention to the importance of anticipating dying in the current rehabilitation culture of nursing homes. It is proposed that by acknowledging the importance of both the *system* and the *lifeworld* in end-of-life care, a recoupling is made possible and as a result, high quality care for dying residents and their families is achieved.

This reciprocity between the nursing home *system* and the *lifeworld* of its staff is of vital importance for nursing home organisations, at this present time. It may play more of a role in staff recruitment and retention of staff than those running nursing home systems are prepared to acknowledge.

8.2 HABERMAS'S THEORY OF COMMUNICATIVE ACTION AND ITS RELEVANCE TO BRINGING ABOUT CHANGE

The two main actions undertaken in this study have been discussed drawing on Habermas's (1987a) theory of the *lifeworld* and the *system*. In continuing this discussion and still in light of Habermas's *Theory of Communicative Action,* I now reflect on insights that I have gained about the process of doing action research.

Action research is a methodology that continues to emerge (Reason & Bradbury 2001). The interest in this emergence is proved by the critical discourse in a number of books written on the theory and practice of action research since I began this study in 2000[62]. The original aim of the study was to use action research to develop staff knowledge about high quality end-of-life care as they cared for residents ending their lives in nursing homes. For this I looked to critical social theory as a theoretical framework. The work by Carr & Kemmis (1986), albeit from within educational action research, became very relevant (see Chapter 3). One of the unique aspects of critical or emancipatory action research is:

> *'...helping practitioners to develop a critical and self-critical understanding of their situation – which is to say, an understanding of the way both particular people and particular settings are shaped and re-shaped discursively, culturally, socially and historically.' (Kemmis 2001, p.92)*

As has already been explained in Chapter 4, focus groups, interviews and participant observation were used to try and tease out some of the difficulties in relation to end-of-life care and the nursing home setting. However, as Kemmis (2001) goes on to note:

---

[62] To name just a few of these books all highlighting emerging theories about action research: McNiff & Whitehead (2002); Reason & Bradbury (2001); Winter & Munn-Giddings (2001); Coghlan & Brannick (2001); Day, Elliott, Somekh & Winter (2002).

> *'[Action research] aims to connect the personal and the political in collaborative research and action aimed at transforming situations to overcome felt dissatisfactions, alienation, ideological distortion, and the injustices of oppression and domination.' (p.92)*

It is in the connecting of the personal and the political that I believe action research is at its most complex. However, this is one of action research's central functions and one that I have come to value when bringing about change to end-of-life care in nursing homes.

In his *Theory of Communicative Action*, Habermas (1987a) believes that within the increasing complexity of systems, not only is there the danger of the uncoupling of the lifeworld from the system, but also that the lifeworld might be 'colonized by the system' (p.333). Both Mishler (1984) and Scambler (1987) take the physician/patient relationship as an example of such a scenario within healthcare, highlighting the danger of the patient's lifeworld being colonized by the technocratic voice of medicine. However, Habermas (1987b) believes that this colonization can be resisted by human action in the form of social movements that value the importance of the *lifeworld* such as women's movements, civil right campaigns, land reform. With reference to research methodology, Kemmis (2001) argues that collaborative action research could be described as such a movement:

> *'It seemed to me that the aspirations of communicative action could be written into or alongside the practices of reflection and discussion characteristic of action research.' (Kemmis 2001, p.93)*

An important part of action research therefore is the emphasis on valuing people as key in enhancing the system that people find themselves working in and wanting to develop. People have the ability to understand complex situations and because of this have the ability to discuss and reconcile difficult situations in order to bring about change. Change does not just happen; it requires negotiation between the differing parties involved. A fundamental aspect of action research is working 'with' people in the field and not 'on' or 'for' them (Reason 1988).

In this section, I would like to highlight the criticalness of dialogue in action research. In particular I want to highlight the importance that Kemmis (2001) gives to the provision of a 'communicative space' in relation to *doing* action research. I re-examine reflections on participation and power that I made at the end of Chapters 5 & 6, and how there might have been greater understanding, especially in NH1, if there had been a greater emphasis on the provision of dialogue through a formal 'communicative space' rather than just within the space allocated for the actions. I highlight the significance of specifically making time for dialogue across differing levels of the nursing home system (staff and management) in order that participation in an action research study and issues of power can be worked through.

8.2.1 Providing a 'communicative space'

In this action research study, where the aim was to enhance development about end-of-life care and where possible bring about change, I realised the importance of dialogue over and above the time given to the implementation of differing actions. Innovative actions are important, but engaging people from the different levels of practice and management in dialogue is necessary in influencing the sustainability of change. In his work of relating Habermas's *Theory of Communicative Action* to action research, Kemmis (2001) states:

> *'Part of the task of an action research project, then, is to open communicative space and to do so in a way that will permit people to achieve mutual understanding and consensus about what to do, in the knowledge that the legitimacy of any conclusions and decisions reached by participants will be proportional to the degree of authentic engagement of those concerned' (Kemmis 2001, p.100).*

For Kemmis (2001), the first step in action research, and one that is central to an on-going project is a place of dialogue and the opening of a 'communicative space'. Such a space 'brings people together around shared topical concerns, problems and issues' (Kemmis 2001: 100). This had occurred during the exploratory phase with staff caring for the residents in NH1 and NH2a, and even during the CLGs. I had also interviewed the nurse managers and the owners of the nursing homes separately about their understanding of end-of-life care. As a result of this we had discussed all together how to take things forward. At this time, I was very conscious of the 'think, plan, act' cycle (Stringer 1996) of Lewin's original cyclical structure of action research. On reflection I believe more of a 'communicative space' could have been given for dialogue *across* the system through provision of a 'communicative space'. It was only when I was in NH2a and NH2b and as I continued to be challenged by the literature on action research that the significance of systematic dialogue became more apparent.

> *'Just finished reading 'Action Research in Practice' (1998) – excellent chapter by Kemmis & Weekes who move 'action research' from seeing it consisting of changing degrees of spirals of action, to dialogue – and so to collaborative action research.' [Methodological note in fieldnotes, 19.07.2002]*

Right at the outset of the research, it had been my intention to have monthly meetings with the nurse manager in NH1 (see Chapter 4), thus opening up dialogue with management. After a couple of meetings, and because the nurse manager was so busy, I felt at the time that the CLGs would suffice as a place where issues could be raised and discussed. However, the CLGs in NH1 and NH2a concentrated on clinical issues around the recent death of residents and the support of staff. They did not address issues about the *system*. My attempts to try and address such issues in what I now can see, in light of Kemmis's writing on a 'communicative space', was an ad hoc way (see Section 7.7.1), made me realise the importance of sustained dialogue across the differing levels of practice and management.

In hindsight, it would have been beneficial if a formal 'communicative space' in NH1 could have been established early on in the study. Such an arrangement would have provided an opportunity to invite people from differing levels of management and practice to have a regular on-going discussion. Firstly, initial meetings with the nurse manager might not have been cancelled; and, secondly, encouraging a dialogue with a small group of people from all the differing levels of the nursing home might have empowered staff in discussion about the system, as well as establishing staff involvement more as co-researchers.

In NH2a things were different. I had realised the importance of on-going discussion with management as a result of my time in NH1 – not only with the nurse manager but also higher up within the nursing home system. Nonetheless this was time consuming, as I did not speak with the various managers at the same time. It did, however, work; and because of the communication system in place throughout the larger nursing home organisation, people higher up within the organisation including the executive board were kept informed of the research. But the meetings consisted of me meeting with separate managers; they were not part of what I believe Kemmis is trying to highlight in writing about a 'communicative space'.

Where I believe a 'communicative space' did take place was in NH2b with the introduction of the ICP (integrated care pathway – see Chapter 7). Here, staff formed a group that included people from differing management and practice levels (including untrained care assistants). The group met regularly not only to develop and implement the ICP documentation but also to discuss how we managed the whole process. Issues for the nursing home system such as where to keep the ICP documentation[63] were teased out. Because everyone in the group wanted the ICP implementation to work they were willing to listen to each other. A 'communicative space' is about gaining mutual understanding and negotiating together how change can happen.

> *'To recognize that [communicative space] as an element of communicative action is to acknowledge that the orientation to mutual understanding and consensus arises in all sorts of ways, around all sorts of practical problems and issues, and that people must constitute a communicative space...' (Kemmis 2001, p.100)*

---

[63] This was when management wanted the ICP documentation to be kept in the staff office. Staff in the core group representing practitioners caring for the residents wanted the documentation in the resident's bedroom. There was considerable discussion on the 'for and against' of where to keep the documentation. I was able to help negotiate and strengthen the voice of practitioners. Having the document in the resident's room would mean less time was wasted going to the office to complete the ICP and that it was more likely that 4hrly assessments would be completed.

In continuing this discussion I would now like to re-visit two specific aspects of collaborative action research: namely, participants as 'co-researchers', and issues of power and politics in the organisation (Meyer 2000). I continue the discussion of how, in opening a 'communicative space', provision is made whereby important aspects of doing action research can be clarified.

i) Participants as 'co-researchers'

In more traditional research paradigms the division between 'researcher' and 'researched' is more marked than in action research (Meyer 2000). It could be argued that in setting up the exploratory period in the way I did, I was working from a more traditional interpretive paradigm. In order to understand death and dying and how it was managed in the nursing homes, I used an ethnographic style of investigating the issues. Staff took part and shared their concerns through focus groups and interviews, and talked about how they would like to take things forward; and I undertook participant observation that often verified the issues that were being raised (see Chapter 5). However, by choosing this way of collecting the initial data, I was being seen as the researcher, and their role as co-researchers was not particularly accentuated. Their involvement in researching the issues was quite passive. As Meyer (2000) advises:

> *'... the level of commitment required in an action research study goes beyond simply agreeing to answer questions or be observed' (p.178)*

Staff were involved in deciding how they wanted to take things forward and staff in NH1 were extremely eager to see their practice change. However, the nurses' and care assistants' voice had only been heard on a 'one off' occasion i.e. when I fed back the results of the exploratory phase. In order to sustain change, it was their position as co-researchers and their voice across the nursing home system that needed to be heard *repeatedly*. This lack of participation as co-researchers might also have been complicated by the history of NH1 and the fact that so many staff had left as a result of the change in management. If a core group of co-researchers had been formed, alongside the action, then their participation as co-researchers in the action research study would have been stronger. It would have meant that I could then have supported *their* voice on an on-going basis. As it happened, it was my solo voice as an 'outsider' that was most often heard, which was more easily tempered by management.

In NH2a, the flatter management structure meant that individual voices were more easily heard. I was also working with a system that was open and ready to change (see Section 5.2.1). However, there was no core group of co-researchers. The participation as co-researchers was mostly between the nurse manager and me. As co-researchers we were more like Titchen & Binnie's (1993a) 'double-act' of insider and outsider[64] rather than encouraging staff as co-researchers.

However, I believe participants became much more like co-researchers after the nurse manager in NH2a left. Because of the sudden change in leadership, and in anticipation of staff leaving, I did an evaluation that provided an opportunity for staff themselves to give further direction on how they would like to develop end-of-life care in NH2b. As a result, a small core group of people, very interested in palliative care, including a staff nurse who became an important 'insider', was formed to discuss end-of-life care and to adapt and introduce the ICP documentation in NH2b (see Chapter 7). The core group who wanted to introduce the ICP documentation bridged different managerial levels as well as disciplines: staff nurses, nurse manager, care assistant, GP, and a representative of the regulatory organization (Care Commission). Their voice as co-researchers was being heard across the system. A comment from my fieldnotes at this time:

> *'A greater understanding of action research I believe has happened as I have gone through the project. My move from NH1 to NH2a and then with the new manager in NH2b has been a huge learning curve for me in the doing of action research. I believe I am at last working more collaboratively.' [Reflective fieldnotes, 29.07.02]*

Edmondson (1996), in a critique of competing theories of organisational intervention and action research, observes that where an ethnographic style is used to slowly build

---

[64] In their research Titchen & Binnie (1993a) used what they called a 'double act' where one researcher was an 'outsider' to the organisation and the other an 'insider' i.e. part of the organisation. Titchen & Binnie found this extremely useful.

trust and understand an organisation over time, such a method 'may be better at describing the status quo rather than changing it' (Edmondson 1996: 577). Collaboration between staff in the nursing homes and me was a reality. But participation as co-researchers, although often referred to with staff, was not such a reality in NH1 and NH2a as it was in NH2b. In hindsight, staff needed to be much more involved at a level in the system where changes that were being initiated could be sustained.

ii) Politics and power

Having discussed participation as co-researchers in the previous section, I now turn to how politics and power, present in any change initiative, might have been handled differently within a 'communicative space'. For this discussion I consciously reflect further, albeit briefly, on the reflexive discussion of Chapters 6 and 7 (see Section 6.7.1 and 7.7.1).

Being involved in diagnosing what might or might not require change or development in an organisation is not easy. There is a need for political awareness in order to understand and work with the different lives of an organisation: the formal public life that represents how it comes across on the outside; and the informal life that is experienced by its members (Coghlan & Brannick 2001). The latter only emerges after a number of weeks or even months of being in an organisation.

> *'organizations are centres of love, hate, jealousy, goodwill and ill will, politics, infighting, cliques and political factions; a stark contrast to the formal rational image which organizations tend to portray.' (Coghlan & Brannick 2001, p.54).*

Senge (1990), in his theory of bringing about change in organisations, seeks to increase the participation of managers by having them diagnose their own system rather than have someone come in and do the diagnosis. Although the staff were all involved in some way or other in diagnosing their own system, management in NH1 were not so involved. This may have increased misunderstanding in relation to change in this nursing home. When I interviewed the nurse manager and owners at NH1, they believed that end-of-life care in their nursing home was good and could not see how it might be improved[65] (despite asking me to come). They were leaving it up to me to come up with the ideas. They appeared quite content for me to engage those staff involved with the day-to-day care in discussion. At the time I thought this appropriate, as the owners had no healthcare background. In the focus groups (see Chapter 4) a deliberate decision was made not to have managers and practitioners together in case staff felt inhibited. As Chenworth & Kilstoff (2002) describe:

> *'In one of the centres, the appearance of the Director of Nursing at focus group meetings restrained staff's involvement in decision-making.' (p.241)*

Staff appreciated not having management present at the focus groups. However, not having management present appeared to reinforce management's hierarchical position – a position that actually became more powerful when they chose not to address some of the issues that staff wanted to focus on. My reporting back the results of the exploratory phase involved making judgements that inevitably questioned organisational and individual practice. As reported in Section 5.7.1, the owners' response to the exploratory phase report in NH1 was to say that my remit was to report on palliative care issues and not organisational issues. For management, the report probably felt like sabotage (Williamson & Prosser 2002). However, action researchers encourage the asking of questions that are quite political in nature, such as: How can we do things differently? (Williamson & Prosser 2002).

With hindsight it was important that management contributed more to diagnosing issues *alongside* practitioners. However, the focus groups were certainly not the place for this to happen. The same core group of staff comprising co-researchers, as described in the previous section, could also, as happened in NH2b, have fulfilled the role of bringing practitioners and management together. This might have reduced fear on both sides, and, at the same time, encouraged a greater respect and a flatter power base. It might also have provided less opportunity for the hierarchical power to be perceived as non-contradictory.

---

[65] 'Staff not self aware to identify change' is one of thirteen factors identified by Meyer et al (1999) as resistance to change – this is discussed further in section 8.3.1 under 'sustaining change'.

Chenoweth & Kilstoff (2002) report that a flattened management style allows staff to participate more easily in the actual decision-making involved in change. This was the case in NH2a. I also had regular meetings with higher management in the larger nursing home organisation, albeit on my own, which kept them abreast with what was happening. When the new nurse manager in NH2b arrived, because of the on-going dialogue about the study higher up in the organisation, she eagerly took on the responsibility of supporting staff in how they wanted to take the study forward.

The politics of doing action research were very different with the differing management styles of the nursing homes involved. It must be stated that a strong hierarchical structure to management is not necessarily wrong. It is one way of organisational management. The owners of NH1 wanted nothing more than the best for their residents. It could be argued that an over identification on my part with the *lifeworld* of the staff in NH1 might have triggered a tightening of power on the part of management. However it also appeared that management had lost interest:

> *'The [project] was welcomed enthusiastically initially by management and staff but the management soon lost interest and the support was not forthcoming from them to implement changes which would benefit caring for the dying' [N1, NH1: evaluation questionnaire]*

Chenoweth & Kilstoff (2002) experienced power issues in all three of their nursing homes where they were undertaking an action research project. Management were enthusiastic about the research at the beginning but this then waned. They also found that management became less supportive of decisions being made by participants actively involved in the action research. The political nature of organisations is at the heart of change. The growing lack of interest within management may not be unusual in undertaking action research in nursing homes:

> *'At first, management in all [three] of the centres were enthusiastic about the initial implementation of the action research process and supported it fully. However, as group meetings and interviews proceeded, taking both time and commitment to sustain,*

> *management and senior staff began to resist the continuation of the process'. (Chenoweth & Kilstoff, 2002:.240)*

These authors also followed a descriptive approach to the exploratory phase prior to the action. It could be argued that they too might have been more successful if management had played a fuller part in diagnosing their own organisation. This reinforces the idea that management must be fully integrated and committed at the beginning of an action research study if power and political issues are to be understood. It would appear from both Cheoweth & Kilstoff's study and my study that inherent aspects of the nursing home system need to be addressed in order to reduce the impact of organisational politics when undertaking action research.

It is argued that action research is about dialogue across the system within a 'communicative space' where both management and those involved in practice are present. Habermas's (1987a) T*heory of Communicative Action* adds an important discussion that helps acknowledge and support subordinate groups when undertaking action research. Realising the importance of regular on-going negotiation with people from management *and* practice across the system is likely to keep up the momentum of the research and flatten power bases.

I have discussed the importance of dialogue and negotiation within a 'communicative space' in order to address power issues whilst undertaking action research. When this is done as an on-going activity with people interested in bringing about change, it enables staff to be more involved and take more responsibility as co-researchers not only in the project but also in diagnosing issues within their own setting. Such systematic dialogue may open up opportunity for greater democracy where powerful hierarchies are present in nursing home organisations. It may also bring about greater collaboration and responsibility for the changes that both practice and management might want to take forward.

8.3 THEORETICAL IMPLICATIONS

The implications of what has been discussed theoretically about action research and the knowledge drawn from Habermas's *Theory of Communicative Action* are now considered. This section examines sustainability of change in action research and how both of the actions developed in this thesis might be used to develop quality end-of-life care in care homes.

8.3.1 Sustainability of change

Resistance to change (Smith 1989; Meyer 1995; Meyer et al. 1999; Bellman 1999) is more commonly addressed in the action research literature than *sustainability* of any change. In many ways this is understandable; if what inhibits change is addressed, then sustainability of that change is hopefully achieved. However, I do not necessarily feel that this always happens in the complex context of nursing homes (see Chapter 2). Long-term sustainability often requires a stable workforce and a necessary trust being built up over time between practitioners and management. Sustainability of appropriate change is increasingly important in light of less and less financial resources, and a diminishing workforce in nursing.

I believe that bringing about sustainability of change in nursing homes is more complex than Balfour & Clarke (2001) make out when they state that hospital nurses themselves can bring about change from a 'bottom-up approach' to change. Staff in many nursing homes are isolated from innovation and the influence of education (Katz et al. 1999). The lack of a learning culture (see Chapter 5) compounds these problems. There are also fewer nurses in nursing homes than in acute hospitals, with the majority of staff in nursing homes being untrained. Often, those who do voice their concerns do not feel listened to (see Section 5.3.3; Forbes 2001).

Disappointingly, there appeared to be little sustainable change to the development end-of-life in the care culture of NH1. Despite the CLGs developing staff critical understanding about end-of-life care, various aspects of the nursing home system itself became a barrier to change. Not only was I aware of this; but staff involved in the project also reported it:

> *'Apart from the above mentioned aspects which I have personally benefited from, I don't feel there have been any significant changes in respect of end-of-life care due to continuous staff changes and shortages.' [N1, NH1, final evaluation questionnaire]*

Meyer et al. (1999) writing about the factors that inhibit and facilitate change when undertaking action research, have highlighted thirteen inhibitory factors and ten facilitative factors related to healthcare settings. Following my involvement in NH1, I could identify at least seven[66] out of thirteen *inhibitory* factors or barriers towards change. I have reason to believe that some of these factors might have been less inhibitive if a 'communicative space' had been established. A 'communicative space' might have encouraged greater management commitment, championed professional development and eased communication about change between those in practice and the management.

When moving to NH2, I realised I had chosen a nursing home (one of the twelve nursing homes to originally volunteer) where I could identify at least 7 out of 10 facilitative factors[67] towards change. However, even in NH2a things were not easy especially when the nurse manager decided to hand in her notice after only eighteen months of being nurse manager. Nonetheless during this time mutual trust and respect between staff, management and myself regarding the study had grown. Significant change happens over time. Having a comprehensive knowledge of the organisation and its staff is one of four aspects identified by Miller et al. (1998) as an important lever for change. As an action researcher, the time spent in NH1, NH2a and NH2b felt like a maturing process as I began to appreciate the complexity of the action researcher's role. The complexities

---

[66] Inhibitory factors in NH1: unstable workforce; lack of talking/supportive culture; lack of management support; lack of enthusiastic leader; task-orientated practice; lack of commitment; low morale.

[67] Facilitative factors in NH2a/b: Commitment; talking/supportive culture; management support; multidisciplinary teamwork; enthusiastic leadership; time/energy/resources; appreciation that change is difficult; 'inside' researcher; stress/conflict in area so ready for change; appropriate level of knowledge/skill/confidence

and challenges for those leading change is widely acknowledged (Redfern & Christian 2003); the role requires experience across a range of competencies including research, management and leadership.

The 'communicative space' that developed in NH2b accommodated different people from the different levels of the nursing home hierarchy. Change was sustained when the culture of end-of-life care in NH2b was challenged by:

i) the introduction of a system for quality end-of-life care (ICP) that directly confronted the functional rehabilitative culture in the nursing home and the lack of openness towards death and dying;

ii) the 'insider' staff nurse in NH2b who was respected by both staff and management for her previous knowledge in palliative care;

iii) the formation of a 'communicative space' where co-researchers (practice and management) from within and outside the nursing home formed a 'core team' to adapt the ICP documentation;

iv) the ownership of the ICP documentation by management, care assistants and nurses who were all involved in teaching staff about the ICP documentation prior to its implementation.

Two years after the introduction of the ICP document, despite a number of changes within the organisation including another nurse manager, the ICP documentation in NH2b is still in use.

In order for any change in nursing homes to be sustained over time, the process in action research must involve both practitioners *and* management, thus flattening hierarchies (a bottom-up *and* a top-down approach). The verbal consent of managers, and even enthusiasm, of management is not enough. Instead, management need to be represented and involved alongside practitioners in changing practice as negotiation is made across the differing levels of the nursing home. Action research, as a way of researching and changing practice, is time intensive. As Chenoweth & Kilstoff (2002) and this study have shown, management can easily lose interest. Sustained change cannot occur therefore without a negotiating process with both management and practitioners *throughout* a study.

Besides a flatter management style in NH2a there was also a staff nurse who was not only very enthusiastic about the study but was also respected for her palliative care experience. Gradually over the months in NH2a, she became an 'insider'(see Chapter 3). This position became more established following a short time spent at the Hospice. As the 'insider', she took responsibility for introducing the ICP following the new nurse manager's arrival (NH2b); while I worked from the outside. She was very supportive of me, but her owning the responsibility alongside other staff within the nursing home is what helped to sustain the change.

In highlighting the usefulness of the 'insider' model for NH2a and NH2b, this is not to say that there were no enthusiastic staff in NH1; there were. But unfortunately in NH1 there was less respect and encouragement for the palliative care skills that these staff demonstrated (see Section 5.7.1).

8.3.2 The CLGs and/or the ICP documentation

Within this thesis two actions were instigated in the nursing homes. I would consider both of the actions undertaken to have been appropriate. Both actions arose inductively out of the nursing home contexts as a result of the exploratory phase and working alongside staff caring for dying residents. There was evidence that both actions were able to develop knowledge about quality end-of-life care (see Table 6.2 and Table 7.1). The CLGs encouraged staff to reflect critically on practice following the death of a resident as a way of learning to improve practice. The ICP document encouraged staff to think critically about attaining goals as difficulties arose while caring for a dying resident and their family. Perhaps it could be argued that the CLGs only passively addressed the rehabilitative culture of nursing home care; the ICP documentation on the other hand was a specific guide for staff, modelled on the person-centred/holistic practice of palliative care, that had a much more direct influence on the nursing home culture.

Because of the unstable context in nursing homes and their isolation from innovative practice on-going in the NHS, I do believe that a method such as the ICP for the last days of life was extremely useful. Unlike when staff left, the documentation remained in the nursing home. It was also being avidly promoted from within NH2b, with new staff being inducted about it.

The different actions addressed different aspects of the organisation – the CLGs addressed the importance of the *lifeworld* of staff around end-of-life care and the necessary emotional and intellectual support necessary for staff in the nursing home. The ICP documentation addressed the functional rehabilitative culture within the nursing home and gave death and dying its rightful place. Both actions could have an important part to play in the development of practice in this area.

Earlier in this chapter (see section 8.2), emphasis was given to the important balance between the *lifeworld* of staff and the nursing home *system* in the development of quality end-of-life care. It could be argued therefore, that, when bringing about change in end-of-life care in nursing homes, and where it is important that change is sustained, both aspects (*lifeworld* and *system*) need to be considered. It was therefore legitimate to see whether by joining these two actions together within a pilot practice development initiative, development of quality end-of-life care could be achieved.

8.3.3 Closing the quality end-of-life care practice-theory gap in nursing homes

Directly as a result of the action described in this thesis, a practice development initiative to introduce high quality end-of-life care in eight independent nursing homes was undertaken (Hockley et al. 2004, 2005). The basis of the study was to further pilot and evaluate the implementation of the ICP documentation that had been adapted in

NH2b, and at the same time use the CLGs to support its implementation. Key champions were appointed as 'insiders' (Titchen & Binnie 1993) by management in each of the eight nursing homes. The key champions were given responsibility for implementing the ICP documentation in order to encourage ownership and sustainability in much the same way as in NH2b. They were supported through monthly action learning sets (McGill & Beaty 1995) at the Hospice, while staff in the nursing homes were supported collectively through monthly CLGs held in each of the nursing homes. These sessions simultaneously helped staff to reflect on the care given to the residents who had died and their families, as well as give staff an opportunity to learn more about quality end-of-life care through the completion of the ICP documentation.

The final evaluation of the implementation of the ICP document in the eight nursing homes (Hockley et al. 2004, 2005) revealed that staff felt more confident in their ability to achieve quality end-of-life care. However, those nursing homes that started with less palliative/end-of-life care skill and knowledge at the beginning of the study needed more help and time for their competence in end-of-life care to improve. Nonetheless, with only a 9-month contact time, in which forty-one ICPs were piloted across the eight nursing homes, the evaluation reported considerable improvement in end-of-life care, and those aspects that impacted on the culture of dying in nursing homes are highlighted in Box 8.1.

Box 8.1: Improvements as a result of implementing the ICP documentation in eight independent nursing homes (Hockley et al. 2005)

- improved teamwork
- more meaningful communication with dying residents/families
- improved critical thinking around palliative care knowledge to influence practice
- greater openness around death and dying
- nurses/care assistants taking more responsibility in recognising and marking the dying process

As a result of their involvement in the initiative, the nurse managers of three out of the eight nursing homes actively changed management structures to reflect the change in culture towards end-of-life care. In six out of the eight nursing homes, death and dying became a more central focus of care as a result of successfully implementing the ICP documentation. This preliminary work to test such a development model mirrors some of the outcomes of this study.

8.4 CONCLUSION

In this chapter I have used Habermas's (1987a) *Theory of Communicative Action* as a framework from which to tentatively explore the relevance of the two inductively derived actions developed in the study nursing homes. I have highlighted, from Habermas's (1987a) theory, the important balance between the *lifeworld* and the *system* when bringing about change in relation to end-of-life care in nursing homes.

I have discussed how the increasing complexity of the nursing home *system* may be unprepared to support the *lifeworld* of its staff when caring for dying residents and their families; how the CLGs helped to address some of the *lifeworld* issues around the individual and collective identity of staff towards death and dying; and how the ICP documentation provided assistance to the nursing home *system* in helping to organise and anticipate the necessary care when a resident was dying.

I have also argued for the importance of a 'communicative space' (Kemmis 2001) being negotiated with management and practice when undertaking action research in the context of healthcare research. Such a space enables power imbalances within a system to be addressed as well as formalising the importance of participants as co-researchers. This in turn is more likely to sustain change.

Finally, I have reported the results of a small pilot study where the two actions of this thesis were combined in order to develop high quality end-of-life care in eight nursing homes. This study confirmed the thrust of this thesis namely, that within the non-specialist setting of nursing homes, practice development should include actions that involve both the *lifeworld* and the *system.*

In the following and final chapter I address the implications for policy, if older people facing the end of their life in a nursing home, and the staff caring for them, are to receive the appropriate support and acknowledgement.

CHAPTER 9

CONCLUSIONS

The aim of the action research study reported in this thesis was to explore with the staff and management of two independent nursing homes (NH1, NH2a and NH2b) their practice in relation to end-of-life care. It was also the intention to initiate actions that could be used to develop staff knowledge and practice in relation to improving the quality of care for residents who were dying, and their families. Finally, the study aimed to describe critically the process involved in such development. Critical action research was the methodology used to frame this thesis with particular reference to Carr & Kemmis (1986) and Kemmis's (2001) exploration of critical action research [grounded in Habermas's *Knowledge and Human Interest* (1972) and *Theory of Communicative Action* (1984, 1987a)].

This study achieved most of its objectives. Staff were encouraged to take an active role in collaborating with the research and to identify their difficulties in caring for residents who were dying. As a result, two major inductively derived action cycles ('collaborative learning groups' following the death of a resident; and the introduction of an 'ICP for the last days of life') were implemented and evaluated in order to address the lack of openness towards death and dying in the nursing homes concerned. The considerable number of deaths that occurred in the study nursing homes highlighted the major role that nursing homes now play in the care of older people at the end of life.

The reflexive discussion at the end of the three major analysis chapters provided an account of what I was learning from *doing* action research and how this in turn influenced how the study continued.

This final chapter will summarise the key findings, identify limitations of the study and discuss the implications for policy and practice development aimed at improving the care given to older people dying in nursing homes.

9.1 KEY FINDINGS

This section highlights some of the key findings reported more fully in previous analysis chapters (Chapters 5, 6 and 7).

9.1.1 Actions to structure the care and support for dying older people in nursing homes

During the exploratory phase of the study, the research highlighted that dying was peripheral to the focus of work in both of the nursing homes taking part (Chapter 5). Many staff were very interested in and committed to providing high quality end-of-life care, but the functional rehabilitative culture within the nursing homes prior to the actions undertaken in the study meant that there was a 'closed' communication about death and dying. The 'Barbie-doll' approach to the care of older people (the washing, dressing and combing of hair), that many young untrained carers are attracted to, may not be sufficient, given the increasingly heavy workload and number of deaths now taking place in nursing homes. The need to get a balance between supporting residents living in the nursing home and a greater openness about death and dying has recently been highlighted by Froggatt (2001a). However, this study revealed that residents who were still well and up-and-about were often very comfortable talking about death and dying; this is also confirmed by reports in recent research literature (Philp 2003; Forbes 2001). Such openness indicates that a majority of older people in nursing homes may not be so thanato-phobic as staff may feel. It also highlights that the problem of talking about death and dying is more likely to arise from staff themselves not feeling confident about what they should say, and in fact in some cases what they are allowed to disclose.

The first inductively derived action to be introduced was the 'collaborative learning groups' (CLGs). These groups were first initiated in NH1 and then continued in NH2a (see Chapter 6). By actively reflecting on the care given to a resident who had died in the nursing home, staff were not only learning how to improve their practice but permission was also being given to speak about death and dying in a way that had not happened before. The process of natural death amongst frail older people in nursing homes and the importance of advance care planning in end-of-life care, which were two very new concepts for many staff, were amongst other issues frequently discussed in relation to being able to recognise dying. Staff were eager to learn about the control of symptoms during the dying phase and the importance of communicating openly with families. The CLGs fulfilled a communicative and supportive role alongside an educational role. Although the evaluation of the CLGs revealed that not every nurse valued reflection as a way of learning, the groups were very much appreciated by untrained carers.

After a number of months facilitating the CLGs, it became clear that what was being learnt by staff in relation to high quality end-of-life care was 'walking out the door' when staff left the nursing home to work elsewhere. The retention of staff in nursing homes is notoriously poor (Redfern et al. 2002). As a result of a formative evaluation in NH2a, documentation to help anticipate appropriate care *before* a resident died was introduced through the development and implementation of an integrated care pathway (ICP). This was done alongside CLGs. The ICP documentation became the second inductively derived action cycle (see Chapter 7). There was considerable evidence (as reported in Chapter 7) that the ICP documentation helped guide and support staff in the organisation of end-of-life care. The documentation also equipped staff with greater understanding about the process of dying and how to ease suffering.

As a direct result of the ICP with its attention to the control of the dying resident's physical and psycho-emotional symptoms in the last days, the resident was better supported. Prior to the study, staff had little understanding about psycho-social and spiritual care, and about the palliative care drugs required in end-of-life care; the ICP documentation contained advice, and enabled staff to bring together these different aspects of end-of-life care. Time given to intensive teaching on the ICP (teaching that was undertaken by the core team in NH2b) highlighted principles of high quality end-of-life care. Due to the commitment of staff in NH2b to maintain this teaching for new staff, the documentation has continued to be used despite further staff turnover. As well as enhancing individual knowledge of staff using the tool, the documentation has enabled basic knowledge about the dying phase to remain in the nursing home. The ICP documentation has helped to bridge the gap between knowledge developed by specialist palliative care and the generalist setting of nursing homes. Two years after the study in NH2b, staff continue to use the ICP documentation.

9.1.2 Acknowledging the *system* and the *lifeworld* in development of end-of-life care in nursing homes

The two actions (the CLGs and the ICP documentation) undertaken to develop staff knowledge in relation to end-of-life care were explored further in Chapter 8 by drawing on Habermas's *Theory of Communicative Action* (1984, 1987a). I highlighted that within Habermas's *Theory of Communicative Action*, the balance between the 'lifeworld' and the 'system' within any one society is crucial. For Habermas, too much attention to social systems and not enough focus on people within society leads to a top-heavy bureaucracy that ignores the important contribution that responsive people can bring to certain difficulties within a society.

In relation to developing end-of-life care in this study, I demonstrated how the CLGs helped to enhance the individual and collective *lifeworld* of staff, increasing their confidence in their care of dying residents and their families; how, in part, the CLGs were able to influence the nursing home culture; and how these sessions provided opportunities for verbal interaction between staff, to tease out difficulties and improve the way they cared for residents who were dying.

I then demonstrated how, within the functional rehabilitative culture of the nursing home *system*, the ICP documentation became a visible tool for guiding end-of-life care, bringing about a greater openness towards death and dying, and alerting staff to the dying process and the needs of families of dying residents. It gave staff more opportunity to take the necessary responsibility for a resident's last days of life. Finally, such a tool gave an opportunity to achieve set goals and monitor outcomes in relation to high quality end-of-life care in nursing homes. Results of a practice development in eight independent nursing homes (Hockley et al. 2005) highlighted how both the actions can be used together in order to develop high quality end-of-life care.

9.1.3 End-of-life care and the differences between the nursing home and hospice context

Being in the nursing homes for a prolonged period of time during the action research study provided an opportunity for me to understand differences between how older people die in nursing homes and how people die in a hospice (see Chapter 7: Table 7.3). It was more likely for residents in the nursing homes to die as a result of multiple pathology, the most common being dementia; unlike hospices, fewer than 10% of residents dying in the nursing homes had a diagnosed cancer. It was evident that the cognitive impairment that accompanies dementia made palliation of symptoms at the end of life a more complex issue, especially in light of the lack of multi-disciplinary working and the high percentage of untrained staff.

The 'prolonged dwindling trajectory' of frail older people (Lynn & Adamson 2003) was a very obvious and often discussed feature of nursing home care (see Section 6.4.1). The emphasis on functional rehabilitation as against palliative rehabilitation compounded problems in diagnosing dying within such a trajectory. Because of the lack of attention to advanced care planning, many frail older people regularly 'bounced back' from death's door (see Section 7.7.2) as a result of having further antibiotics for pneumonia only to die a few weeks/months later. Such a phenomenon appears unique to nursing home care.

Residents were highly dependent on untrained staff for their care; however, unlike patients dying in a hospice where there is a full multi-disciplinary team, residents dying in a nursing home did so quite independent of the medical profession. Nurses shouldered considerable responsibility but many were confused as to the important role they had in the process of end-of-life decision-making. There was a greater emotional tie between staff and resident in the nursing home than in a hospice. Staff had often become like family (Moss et al. 2003) to many residents, because of the length of time residents had been in the home. This close relationship impacted on staff, especially younger untrained staff, when a resident died. There appeared to be more unresolved grief issues amongst staff in the nursing home.

9.1.4 Negotiating change in action research

A further objective of this study was to understand the process by which change came about in the nursing homes. This is highlighted in the study through my engaging in 'praxis' with the theory of action research and its practice. At the end of each of the analysis chapters (chapters 5, 6 and 7), opportunity to reflect critically on the process of undertaking action research, the difficulties of bringing about change, and how what I was learning could be incorporated into the on-going study was highlighted. Bringing about change is never easy. However, I underestimated the power that the owners/managers of nursing homes exerted when it came to addressing nursing practice; and I also underestimated the threat a nurse specialist's skill could be to an authoritative power of a management structure somewhat removed from its staff (see Section 6.7.1).

Section 5.4.2 and Section 8.2.1 highlight greater understanding of the importance of dialogue and collaboration in action research across the different levels of management and practice. However, in Section 8.2.1 my reflections on critical action research also suggest that collaboration is more complex than just involving and collaborating with people; there is a depth to dialogue in critical action research that needs to openly recognise the importance of *negotiation*. There needs to be an actual planned opportunity to 'reach a deal' over issues through negotiation, which I believe is more than simply collaboration: in other words, an on-going 'communicative space' (Kemmis 2001) where there is give and take between people as part of an action research study. Making a 'communicative space' has the potential to appropriately respect and accommodate the intrinsic power within and between people involved in management, practice and research.

9.2 STRENGTHS AND LIMITATIONS OF THE STUDY

Any study design has its strengths and limitations. In this section, issues relating to my expertise as a clinical nurse specialist, the nursing homes and the sustainability of the development, the utility of the ICP documentation, and issues to do with generalisability of this action research study are discussed. The new knowledge that arises as a result of undertaking this study is also highlighted.

The first issue is my expertise in palliative care. As a result of the depth of experience in palliative care gained over the years in practice, I was able to support the practice of end-of-life care in the nursing homes involved and was comfortable discussing any subject that might be raised in relation to death and dying. Having this knowledge of palliative care certainly helped gain credibility with staff involved in the research in their care of residents in the nursing homes. Someone *without* this experience is likely to have adopted a very different approach to the study that might have been more similar to Holter & Schwartz-Barcott's (1993) 'technical collaborative' or 'mutual collaborative' approach (see Section 3.1.3). They would not have been able to critically appraise clinical situations in the same way – something that was an integral part of facilitating the CLGs, and the development and adaptation of the ICP documentation. However, it could be argued that being an experienced nurse specialist might also be a limitation of the study. It is unlikely that someone else would have the unique practice experience in palliative care that I have been fortunate to have. Nonetheless, one is reminded that action research is a different methodology to that of quantitative research; action research is context-specific (McNiff & Whitehead 2002). No action research study can be the same; it is like dipping one's foot in a river where the free running water is always changing; the situations experienced in the nursing home are exclusive to that specific period in time. It could also be argued that my palliative care experience was a potential threat to management – certainly this became an issue in NH1 (see Section 6.7.1). Nonetheless, I do believe the actions derived were in part due to an in-depth understanding of the complexity of end-of-life care and a personal desire to improve practice within an area that has previously had little palliative care support.

Both independent nursing homes (NH1, NH2a and NH2b) that were selected to take part in the study were known across the City for their quality of care. Both had a majority of residents who were contributing privately to their funding (although one of the nursing homes was non-profit making). Opportunity had been given to all independent nursing homes across the health authority to be involved in the study, but only one nursing home, out of the twelve nursing homes which volunteered, was ordinarily funded through social services. This was the nursing home that I had to withdraw from because of lack of permanent trained nurses (see Section 4.3.2). Even though the nursing homes involved in this study did have problems with staff retention and recruitment, both were reasonably stable as far as a core group of staff were concerned during the time of the study. It is unlikely that the depth of development of end-of-life care could have been achieved in nursing homes where there was more generalised unstable staffing. However, this clearly does not reflect the situation in some nursing homes that cope with more instability. It would be important for an action research study to be carried out in independent nursing homes funded more specifically by social services.

Nonetheless, sustainability of the changes within the actual nursing home culture was problematical, even with the use of an action research methodology. In NH1, despite important work with the formation of the CLGs, and the individual knowledge of staff in the nursing home being enhanced, I am unsure that there was any significant change to the nursing home culture as a result of this action research study. After I moved to

NH2a, I learnt that many of the staff had left NH1; and although the CLGs continued for a short while, I was later to learn that they had stopped. I was conscious that I had not encouraged the facilitation of these groups being taken on by staff while I was still present in the nursing home. In effect, the staff's lack of experience in palliative care might have hindered this. In hindsight a better exit strategy might have been for a local Macmillan nurse to fulfil a facilitative role in NH1.

In NH2b, a greater change to the nursing home culture was sustained. Whether this was due to the ICP documentation being a more tangible contribution to change or because of the quality of the 'insider' who already had some palliative care experience, or for both of these reasons, is difficult to know. Certainly the skill of this 'insider' staff nurse and the ability she had in taking responsibility for an area she was keen to develop herself were important factors. The ICP documentation provided a tool for the inexperienced and became an on-going learning tool. Being involved with this nursing home (NH2a and NH2b) for nearly two years, during which time I was available to promote the appropriateness of a palliative care approach to the nursing home culture was more time than I had spent in NH1. This too can also be seen as a limitation. Who in undertaking research can spend two years in one setting?

Although the richness of the data reported in this study will help those in other nursing homes identify with the study, making generalisations across settings may not be appropriate. Action research is context-specific (McNiff & Whitehead 2002) and so generalisations from one context to another need to be taken with caution. However, Meyer et al. (1999) do demonstrate that making generalisations from action research studies is not as inappropriate as some critics might suggest. Meyer et al. (1999) use findings from a study by Meyer (1993), with particular reference to factors that facilitated/inhibited change in the study, and compare these findings with the difficulties of change in 75 action research studies selected and reviewed systematically. They were able to show that the results with regard to the ease and difficulty of bringing about change *were* generalisable. Interestingly, the difficulties of bringing about change in this action research study are not dissimilar to some of the results of Meyer et al.'s (1999) systematic review (see Section 8.3.1). It remains to be seen how transferable the tools developed in this study are to other nursing homes. As many of the issues between the two nursing homes were also supported by the literature from other research in independent nursing homes, the wider relevance of the CLGs and the ICP documentation would be important to ascertain in further practice development and research.

The ICP document, adapted by the core group in NH2b, had originally been devised by specialists in palliative care. It did have a strong cancer-orientation and Froggatt (2001) highlights the danger of assuming that the hospice model of palliative care can be transferred directly to the nursing home context. Nonetheless, staff in NH2b who were well experienced in the care of older people alongside one of the GPs, spent a considerable amount of time adapting the ICP documentation for the nursing homes context. However, a limitation of the study is that the ICP documentation was only piloted on four residents in NH2b before I had to leave the field at the end of the study. Feedback on the used ICP documentation following the deaths of these four residents did mean that wording in the document was further adapted (see Chapter 7) but further adaptation is almost certainly necessary and the document will require further testing in other nursing homes before it could be recommended for use across the independent nursing home sector. There is also a danger that some nursing homes wanting to implement the ICP documentation may not realise the extensive education and motivation required before it can be used successfully.

As has already been recorded, the small numbers that were involved in evaluating both the action cycles is a limitation of this study (see Section 6.6 and Section 7.8). Although a 78% response rate to the evaluation questionnaire was very good in NH1, the number of questionnaires sent out was only nine. There had been a slow trickle of staff leaving NH1 during the 10 month-period of my involvement, and I had not realised its impact on an objective evaluation at the time. Staff replacing those who left were often from the agency; and although some were very interested in the study, no agency staff became involved in taking part in the CLGs. When new permanent staff did arrive, some did not stay very long and others were by this time only loosely involved in the action research, so did not fill in a questionnaire. In NH2a thirty-five questionnaires were distributed but the response rate was poor (54%) and many of the questionnaires were incomplete. The evaluation of the second major action cycle in NH2b also needs to be treated with caution as only six staff were involved in using the actual documentation. However, those staff in the nursing homes who did return the evaluation questionnaires were people who had been fully involved in the change initiative and so reflect a valid response to the evaluation despite numbers being small. There was also on-going field data that was valuable to the evaluation. In hindsight, I should have given out the evaluation questionnaire each time a staff member left. These relatively small numbers are not dissimilar to other critical action research studies (Titchen 2000; Bellman 1996, 1999) where emphasis was on a qualitative approach.

The use of Habermas's (1984, 1987a) *Theory of Communicative Action* to explore an interpretation of the two major action cycles (the CLGs and the ICP) into a practice development framework may be an over-simplification of Habermas's theory. The theory gave me labels whereby I could explore the significance of the two inductively derived actions. At a basic level it provided a means to interpreting the importance of the *lifeworld* in valuing the emotional and physical labour undertaken by untrained carers and nurses involved in caring for dying residents. The theory also conveniently helped to highlight the importance of the ICP as a tool to guide end-of-life care within the functional rehabilitative *system* of the nursing home. However, I am nonetheless fully aware that this interpretation of the theoretical development of the system and lifeworld is limited; further time was unavailable within the time constraints of this thesis. Using Kemmis's recent work (2001) to explore this further would be valuable.

9.2.1 Contribution to knowledge

Some of the contributions to knowledge have already been highlighted in the previous section. However, this section reiterates the key contributions to knowledge made in this thesis in relation to the development of end-of-life care for older people dying in independent nursing homes.

This has been the first action research study aimed at developing high quality end-of-life care in nursing. Given the increase in deaths, this is an important area for investigation and development. The ten taped CLG sessions, as part of the first major action cycle, provide evidence of new knowledge about important aspects of end-of-life care in older people. They also contribute to an understanding of the different types of learning that took place. The supportive nature of such group work, following the death of a resident, is an important contribution, especially in light of retention and recruitment problems amongst nursing home staff. The adaptation of the ICP documentation in conjunction with staff in nursing homes makes such a document more relevant to the care of frail older people in the last days of life.

The practice development framework (using both the CLGs and the ICP documentation to implement high quality end-of-life care in nursing homes) is a framework responsive to current issues around end-of-life care in nursing home practice. It is an important contribution to how end-of-life care might be developed in interested nursing homes in the future.

A further contribution to knowledge is the further thinking that has taken place in relation to collaboration and a democratic impulse in action research. This study has identified negotiation, not just collaboration, as an important factor in democratic change. Negotiation is more about coming to a point of agreement that highlights a more complex involvement than just collaboration. This has not been highlighted in any other previous study of which the author is aware.

9.3 POLICY AND PRACTICE IMPLICATIONS

It is appropriate to conclude this thesis with some implications for policy and practice. These are necessarily tentative due to the limitations of this research. The study described in this thesis has presented evidence to suggest that the fragmentation that has occurred in the care of frail older people requiring 24-hour nursing care in the UK since the Community Care Act 1990 has resulted in sub-optimal care for those who die in nursing homes. Of course it is likely that end-of-life care was not being adequately addressed in long-stay wards prior to the Community Care Act 1990[68]. Nonetheless, at that time, patients in long-stay wards still had daily input from specialist geriatricians if required. It would appear now that not only is there fragmentation of the care of older people but also that this care has become 'uncoupled' from the overarching NHS system. Recent concern among GPs about workload and remuneration in relation to nursing homes (Groom et al. 2000; Glendinning et al. 2002; Jacobs 2003), raises serious questions about the quality of medical input and equity of service for residents in nursing homes (Glendinning et al. 2002).

This background context, along with results from this study, has certain implications for the regulatory bodies for independent nursing homes, for the management of nursing home organisations, and for those in leadership within the nursing profession and specialist palliative care if the palliative care, of older people in nursing homes is to improve.

9.3.1 Implications for regulatory bodies of independent nursing homes

There is no doubting the greater complexity of care in nursing homes over the last ten years due to the increasing number of frail older people and the subsequent increase in deaths (Kristjanson et al. 2005). A majority of residents in any one nursing home is

---

[68] For example, Graham & Livesley (1983) reported that the needs of dying patients in a long-stay geriatric ward were not appropriately appreciated –and that staff did not recognise the needs of 13 out of 14 patients who were dying.

likely to die within two years of admission (Katz et al. 1997; Hockley et al. 2004). As a result, it is likely that a functional rehabilitation culture may no longer be an appropriate care model for such homes. There will certainly be some residents who are admitted for a short time and who intend to return home; but a care culture that highlights 'palliative rehabilitation' (Hockley 1993), as a more appropriate approach, needs to be considered. Kristjanson et al. (2005) pose a case for a palliative approach to care in nursing homes that is a blend of gerontological and palliative care expertise. Bringing about such a change has enormous implications for those regulating care. A new role for national regulating bodies could be to help lead the way with practice development initiatives, alongside other agencies, and introduce evidence-based guidelines to help develop care in the care home sector.

How to get evidence-based tools, such as an ICP, into the independent nursing home sector, with each nursing home answerable to a different management system, is complex and would pose problems. However, there needs to be a 're-coupling' of services with independent nursing homes so that older people do not suffer needlessly at the end-of-life. This could entail the responsibility for action being equally shared across: national regulatory bodies; nursing home organisations; primary care trusts; health authorities and their managed clinical networks for palliative care; specialist palliative care teams; hospices; and charities interested in the care of older people (NCPC 2005).

9.3.2 Implications for the management of nursing home organisations

The Wanless review of the NHS (2002) has identified the key role that care homes play in the care of older people; and yet the financial position of many nursing home organisations is quite vulnerable (Netten 2003). The advanced, incurable and on-going morbidity of residents in nursing homes is not dissimilar to that of patients admitted to hospices, although obviously residents are likely to stay longer in a nursing home. The hospice movement has attracted considerable community support[69], not only financially but through people volunteering e.g. to help dig the gardens, or run a charity shop. However, there is not this same voluntary help for residents in nursing homes. Many people whom I met during the undertaking of this study could not understand why nursing homes have to close down because of financial problems when residents pay, or contribute towards, the £600 or over per week it costs to care for someone in a nursing home. Nursing home managements admitted to me that they did not make that much of a profit and I often wondered why they did not therefore manage the business from a 'not for profit' status.

With nursing homes being the place where one-in-five people over the age of 65 years will die, better communication and coordination of care between the nursing home management and staff with GPs and hospice services requires attention. There is some evidence that GPs often feel that they are called out unnecessarily to see residents in nursing homes (Williams et al. (1992); however more recent research carried out in Glasgow (Pell & Williams 1999) suggests that nursing home residents *do* require greater input from general practice and that the medical cover for nursing homes needs restructuring. Certainly in NH1, where only one GP practice was involved, and where the GP visited once a week, the availability of the medical information was excellent. Nurse managers of nursing homes should consider such an approach in order that trust and respect can be built up between nursing home staff and their medical colleagues.

Many studies reporting on end-of-life care in nursing homes conclude with the advice to increase education and *'...creat[e] incentives to improve staff recruitment and retention' (Rice et al. 2005: 668).* Difficulties of recruitment and retention of staff are endemic in nursing homes (Redfern et al. 2002; Forbes 2001; Strumpf et al. 2004). There is no doubt that many independent nursing home organisations, especially those that are small, are finding it difficult to survive the financial constraints of the market (Netten et

---

[69] A majority of hospices receive between a half and two-thirds of their financial need through fund raising. In 2005, a bed at a hospice is likely to cost, on average, £1,700 a week [personal communication].

al. 2003). The problems nursing home managements have to attract staff as a result of the National Minimum Wage are considerable[70] (Netten et al. 2003). Recent evidence (Castle & Engberg 2005) reports that moderate-to-high staff turnover in nursing homes influences the quality of care that is given, which in turn must impact on the quality of end-of-life care.

However, recruitment and retention difficulties may be, in part, an effect of issues *within* the nursing home itself, some of which have been highlighted in this study. The nurse manager of a nursing home plays a key role in encouraging a stable workforce (Anderson et a. 2004). As observed in both nursing homes in this study, when the nurse manager left, a high percentage of staff left with her or shortly after the new nurse manager was in post. The quality of the nurse manager's clinical skills and her ability to communicate well with her staff have the capacity to 'break' or 'make' a nursing home team and the nursing home's subsequent reputation. This study also showed that untrained carers require more support and knowledge when caring for residents who are dying. Management bodies of nursing homes need to consider whether their problem with retention of staff is not in some way due to a lack of both clinical and emotional support of their staff in relation to the physical and emotional stress involved in caring for frail residents at the end of life. This study highlighted that the ICP documentation was able to support staff in their knowledge of end-of-life care and helped them in what is a complex situation in the care of dying residents and their families. An important piece of research would be to look at whether increasing the support and development in relation to 'lifeworld' and 'system' around end-of-life care in nursing homes actually influences retention rates.

Managers of nursing homes may be concerned that involvement in a development initiative such as that explored in this study would give staff more work on top of their

---

[70] Establishment of National Minimum Wage has meant that a person can earn as much per hour in a supermarket stacking shelves as a care assistant in a nursing home, and the latter have a significantly heavier load in caring for frail older people who are dying.

heavy workload. However, the development undertaken in this study appears to have motivated staff rather than drain them. Staff were extremely grateful for the time and interest given as a result of the study. The CLGs and implementation of the ICP documentation provided a focus for learning, and seemed an antidote to 'burn out' and 'rust out' (Redfern et al 2002). In many ways, this study could be analogised to a plough revitalising a hard, dried up field. The ground, although rich and fertile, had become hardened and bereft of growth that it could so easily produce. The development (or 'ploughing') undertaken in this study allowed staff to start opening up about death and dying, to think how they wanted to take things forward, and in some situations, allowed considerable growth to occur; not only growth in their own individual staff understanding but also within the culture of the nursing home.

The market-driven economy currently structured around the care of frail older people in care homes can highlight tensions between the espoused values of person-centred care of staff and the 'for profit' values of management (McCormack 1999). With the isolation from the NHS and the market-orientated profile of independent nursing homes, nursing home management might benefit from being more actively involved in creating flatter hierarchical structures such as are found in 'learning organisations' (Senge 1990). This would give more opportunity for the voice of staff to be heard, and would enable a greater collaboration between management and staff in realising the care needs of dying residents and their families. Such a structure advocates personal mastery, shared vision, and team learning, but depends on the involvement of all levels of management and practice.

9.3.3 Implications for nursing profession in leadership

Much of the responsibility for the care of frail older people in nursing homes has fallen on nurses. This is not inappropriate but, as this study shows, there has been little preparation for such a role. Nurses are being called upon to take increased responsibility in care homes (RCP, RCN & BSG 2000) but this study highlights that such responsibility must include palliative care and end-of-life care as a key part of such a role.

In trying to bridge the gap between end-of-life care and the building of relationships with local specialist palliative care, a number of initiatives are reported (Casarett et al. 2001; Ersek et al. 2003; Parker-Oliver 2002; Strumpf et al. 2004)[71]. In the UK, it has been suggested that Macmillan nurses could fulfil an educational role from within the community (Katz et al. 1999). Froggatt (2001) contacted 500 community palliative care nurse specialists concerning their involvement in nursing homes; most visited only when asked and in general only advised on the care of residents suffering from cancer. The nurse specialists' input was not aimed towards a proactive practice development role to empower nursing home staff in their care of older people dying in a nursing home. In fact, only going to see residents with cancer may have resulted in residents who were not dying from cancer being seen as less important. Froggatt's (2001) study highlights the reactive work of palliative care by community nurse specialists in nursing homes in the UK and highlights the often temporary 'sticking plaster' effect of much of the effort being aimed at supporting nursing home staff. If staff in nursing homes are going to be able to reach their potential in end-of-life care and to be empowered to change their practice, then they must be supported through advice and education as well as through more long-term practice development initiatives.

In a study by Parker-Oliver (2002), hospice staff were reported as being frustrated when advising on the palliative and end-of-life care needs of residents in nursing homes because of nursing home staff's lack of ability in treating pain and recognising dying. This research has highlighted the importance of practice development initiatives in heightening nursing home staff awareness of the palliative and end-of-life care needs specific to older people in nursing homes in order to bring staff knowledge to a level that will enable them to communicate more effectively with hospice/community nurse specialists. Building a bridge across this gulf is important – at present the gulf is too

---

[71] Mostly from the USA

wide for most nursing homes to deal with and will require considerable work on both sides if it is to be traversed.

9.4 CONCLUDING REMARKS

Up until now, the hospice movement has taken upon itself the role of addressing the taboo of death and dying. However, Payne et al. (2004) believe that the hospice movement may now be unable to fulfil such a vision because of its increasing association with the NHS[72]. If there is a watering down of the main purpose of the hospice movement, namely care of the dying, nursing homes could play a major role in re-illuminating the importance for such care. I have argued in this thesis that nursing homes' independence from the NHS poses a challenge to the care of older people. However, ironically, if greater attention can be made to this important work within the independent nursing home sector, it may be an opportunity to demonstrate the importance of natural dying to society in a way best described by Phillipe Aries (1981):

> *'Death must simply become the discreet but dignified exit of a peaceful person from a helpful society that is not torn, not even overly upset by the idea of a biological transition without significance, without pain or suffering and ultimately without fear.' (p.614)*

Developing end-of-life care in nursing homes may be the boost that specialist palliative care/the hospice movement needs in order to keep its focus and prevent it from slipping further into the bureaucracy of the NHS system. Nonetheless, it must allow end-of-life care in nursing homes to develop appropriately within its own context rather than

---

[72] Payne et al. (2004) appropriately challenges the specialist palliative care community for what they believe might be another 'curtain' of the taboo of death and dying. Even from within the hospice movement community itself, there are suggestions that its main purpose – to comfort and care for the dying – is being compromised in light of potentially more glamorous profiles. Twenty years after the commencement of the Hospice Movement, Kearney saw cracks emerging as doctors in palliative care concentrated more on 'symptom control' than aspects of psycho-social and spiritual care, and coined the phrase 'symptomatologists' (Kearney 1991). Recent theses have revealed that core strengths of specialist palliative care, namely 'being with' (Haraldsdottir 2005) and spiritual care and dying (Vivat 2004) are not necessarily part of the day-to-day care within hospice units in Scotland, which is a serious concern.

imposing a model developed from specialist palliative care and cancer. If nursing homes are able to rise to this challenge of giving high quality end-of-life care to our frail older population, there may be an exponential effect on society. Although it will nonetheless be a long and difficult journey, those who work in and are involved with older people dying in nursing homes are the people who could finally break the taboo on death and dying in our society, in a way that the hospice movement, as yet, has not been able to.

The research reported here gives some grounds for hope. When the barriers to the provision of high quality end-of-life care were identified in two independent nursing homes, evidence has been provided of two specific actions that help to bring death and dying from a peripheral focus to a more central focus of nursing home care. Support of the *lifeworld* of staff, in their care of dying residents and their families, and the development of a tool to guide end-of-life care within the nursing home *system* have been interpreted as important initiatives in the development of end-of-life care in nursing homes. This study highlights the enthusiasm that some staff in nursing homes have to develop this sort of care. However, taking this development further depends on the linking of nursing homes with the NHS/specialist palliative care and academic units. As Philp (2003) suggests:

> *'We face a big challenge in end-of-life care of older people, not because of demographics, but due to ignorance and prejudice among practitioners and the general public, failing to apply evidence to develop best practice and failing to spread good practice.'* (p.153)

REFERENCES

A

AGS (1997) Measuring quality of care at the end of life: a statement of principles. *Journal of the American Geriatric Society,* 45: 526-527.

AGS (1998) The Management of Chronic Pain in Older People. *Journal of the American Geriatric Society,* 46: 635-651.

Adler P A & Adler P (1994) Observational techniques, in: N K Denzin & Y. Lincoln (eds) *Handbook of Qualitative Research.* London: Sage Publications Ltd. pp.377-392.

Age Concern (1999) *The Future of health and care of older people: the best is yet to come.* Debate of the Age Health and Care Study Group. London: Age Concern.

Alvesson M & Skoldberg K (2000) *Reflexive Methodology: new vistas for qualitative research.* London: Sage Publications Ltd.

Anderson R A, Corazzini K N & McDonald R R Jr. (2004) Complexity science and the dynamics of climate and communication: reducing nursing home turnover. *Gerontologist,* 44 (3): 378-388.

Argyris & Schon (1974) *Theory in Practice: increasing professional effectiveness.* San Francisco, CA: Jossey-Bass.

Aries P (1981) *The hour of our death.* Translated from the French by Helen Weaver. Middlesex: Penguin Books.

Avis M, Greening-Jackson J, Cox K (1999) Evaluation of a project providing community palliative care support to nursing homes. *Health and Social Care in the Community,* 7 (1): 32-38.

B

Badger T G (2000) Action research, change and methodological rigour. *Journal of Nursing Management.* 8, 201-207.

Baines M & Saunders C (1983) *Living with Dying: the management of terminal disease.* Oxford: Oxford University Press.

Balfour M & Clarke C (2001) Searching for sustainable change. *Journal of Clinical Nursing,* 10: 44-50.

Banaszak-Holl J & Hines M A (1996) Factors associated with nursing home staff turnover. *Gerontologist* 36 (4): 512-517.

Bellman L (1996) Changing nursing practice through reflection on the Roper, Logan and Tierney model: the enhancement approach to action research. *Journal of Advanced Nursing,* 24: 129-138.

Bellman L (1999) *Nurse-led change and development.* PhD thesis. Steinberg Collection, Royal College of Nursing, London.

Bellman L (2003) *Nurse led change and development in clinical practice.* London: Whurr Publishers.

Benner P (1984) *From Novice to Expert: Excellence and Power in Clinical Nursing Practice.* California: Addison-Wesley.

Bernabei R, Gambassi G, Lapane K, Landi F, Gatsonis C, Dunlop R, Lipsitz L, Steel K, & More V (1998) Management of pain in elderly patients with cancer. *Journal of the American Medical Association,* 279 (23), 1877-1882.

Bernstein R J (1976) *The Restructuring of Social and Political Theory.* London: Basil Blackwell.

Binnie A & Titchen A (1999) *Freedom to Practise: the development of patient-centred nursing.* Oxford: ButterworthHeinemann.

Biswas B & Ahmedzai S (1993) *The Medicalization of Dying,* in: The Future of Palliative Care: issues of policy and practice. Ed: D. Clark. Buckinghamshire: Open University Press.

Blackburn A M (1989) Problems of terminal care in elderly patients. *Palliative Medicine,* 3: 203-206.

Bottrell M M, O'Sullivan J F, Robbins M A, Mitty E L & Mezey M D (2003) Transferring dying nursing home residents to the hospital: DON perspectives on the nurse's role in transfer decisions. *Geriatric Nursing,* 22 (6): 313-317.

Brazil K, McAiney C, Caron-O'Brien M, Kelley M L, O'Krafka P & Sturdy-Smith C (2004) Quality end of life care in long-term care facilities: service provider's perspective. *Journal of Palliative Care*, 20 (2), 85-92.

Brown M, Grbich C, Maddocks I, Parker D, Connellan P R & Willis E (2005) Documenting end-of-life decisions in residential aged care facilities in South Australia. *Australian and New Zealand Journal of Public Health,* 29 (1): 85-90.

Buchanan D & Boddy D (1992) *The Expertise of the Change Agent.* London: Prentice Hall.

Buchanan R J, Choi M, Wang S, & Ju H (2004) End-of-life care in nursing homes: residents in hospice compared to other end-stage residents. *Journal of Palliative Medicine,* 7 (2): 221-232.

Burak O R & Chichen E R (2001) A support group for nursing assistants: caring for nursing home residents at the end-of-life. *Geriatric Nursing,* 22 (6): 299-305.

Burke K (1999) Taping handovers saves trusts £16,000 a ward. *Nursing Standard,* 13 (23), 77.

C

Campbell H, Hotchkiss R, Bradshaw N & Porteous M (1998) Integrated Care Pathways. *British Medical Journal,* 316: 133-137.

Carlisle R (1999) Do nursing home residents use high levels of general practice services? *British Journal of General Practice,* 49: 645-646.

Carper B (1978) Fundamental Patterns of Knowing in Nursing. *Advances in Nursing Science,* 1 (1): 13-23.

Carr W & Kemmis S (1986) *Becoming Critical: Education, Knowledge and Action Research.* London: The Falmer Press.

Casarett D, Hirschman K B & Henry M R (2001) Does hospice have a role in nursing home care at the end-of-life? *Journal of the American Geriatric Society,* 49: 1493-1498.

Castle N G & Engberg J (2005) Staff turnover and quality of care in nursing homes. *Medical Care,* 43 (6): 616-626.

Checkland P (1999) *Systems Thinking, Systems Practice.* Chichester: Wiley.

Chen S, Melcher P, Witucki J & McKibben M A (2002) Nursing home use for clinical rotations: taking a second look. *Nursing and Health Sciences,* 3: 131-137.

Chenoweth L & Kilstoff K (2002) Organizational and structural reform in aged care organizations: empowerment towards a change process. *Journal of Nursing Management,* 10: 235-244.

Chilvers J R & Jones D (1997) The Teaching Nursing Homes innovation: a literature review. *Journal of Advanced Nursing,* 26: 463-469.

Coghlan D & Brannick T (2001) *Doing Action Research in Your Own Organization.* London: Sage Publications Ltd.

Coghlan D & Casey M (2001) Action research from the inside: issues and challenges in doing action research in your own hospital. *Journal of Advanced Nursing,* 35 (5): 674-682.

Cole J (2003) *Developing a Healing Ministry: a training manual for churches.* London: New Wine.

Connor M J (2004) The practical discourse in philosophy and nursing: an exploration of linkages and shifts in the evolution of praxis. *Nursing Philosophy,* 5(1): 54-66.

Cook A K, Niven C A, Downs M G (1999) Assessing the pain of people with cognitive impairment. *International Journal of Geriatric Psychiatry,* 14: 421-425.

Cook T (1998) The Importance of Mess in Action Research. *Educational Action Research,* 6 (1): 93-108.

Copp G (1997) Patients' and nurses' constructions of death and dying in a hospice setting. *Journal of Cancer Nursing,* 1 (1): 2-13.

Counsel and Care (1995) *Last Rights: a study of how death and dying are handled in residential care and nursing homes.* Available from: Counsel and Care, Twyman House, 16 Bonny Street, London NW1 9PG.

Cowan D T, Fitzpatrick J M, Roberts J D, While A E & Baldwin J (2003) The assessment and management of pain among older people in care homes: current status and future directions. *International Journal of Nursing Studies,* 40 (3): 291-298.

Cowley S (1990) Who qualifies for terminal care? *Nursing Times,* 86 (22): 29-31.

Cox S & Cook A (2002) Caring for people with dementia at the end-of-life. In: J. Hockley & D. Clark (eds) *Palliative Care for Older People in Care Homes.* Buckingham: Open University Press.

Crotty M (1998) *The Foundations of Social Research: meaning and perspective in the research process.* London: Sage Publications Ltd.

Currie L & Harvey G (1997) *The Origins and Use of Care Pathways in the USA, Australia and the United Kingdom.* Report No. 15 (revised 1998). RCN Institute: Oxford.

D

Dawson L & Kass N E (2005) Views of US researchers about informed consent in international collaborative research. *Social Science and Medicine,* 61 (6): 1211-1222.

Davies E (1995) Reflective Practice: a focus for caring. *Journal of Nursing Education,* 34 (4): 167-174.

Davis B & Sumara D (2005) Complexity Science and Educational Action Research: toward a pragmatics of transformation. *Educational Action Research,* 13 (3): 453-464.

Day C, Elliott J, Somekh B & Winter R (2002) *Theory and Practice in Action Research: some international perspectives.* Oxford: Symposium Books.

de Luc K (2000) Care pathways: an evaluation of their effectiveness. *Journal of Advanced Nursing,* 32 (2): 485-496.

de Luc K (2001a) *Developing Care Pathways: the tool kit.* Oxon: Radcliffe Medical Press.

de Luc K (2001b) *Developing Care Pathways: the handbook.* Oxon: Radcliffe Medical Press.

Deahl M P, Srinivasan M, Jones N, Neblett C & Jolly A (2001) Evaluating psychological debriefing: are we measuring the right outcomes? *Journal of Traumatic Stress,* 14 (3): 527-529.

Deutschmann (2001) Redefining Quality and Excellence in the Nursing Home Culture. *Journal of Gerontological Nursing,* August: 28-36.

Dey I (1993) *Qualitative Data Analysis: a user-friendly guide for social scientists.* London: Routledge.

DoH (2001) *National Service Framework for Older People.* Department of Health, London.

Doyle D, Hanks G & MacDonald N (1993) Introduction, in: D. Doyle, G. Hanks & N. MacDonald (eds) *Oxford Textbook of Palliative Medicine.* Oxford: Oxford Medical Publications:

Duffy & Scott (1998) Viewing an old issue through a new lens: a critical theory insight into the education-practice gap. *Nurse Education To-day,* 18 (3): 183-189.

Dunckley M, Aspinal F, Addington-Hall J, Hughes R & Higginson I J (2005) A research study to identify facilitators and barriers to outcome measure implementation. *International Journal of Palliative Nursing,* 11 (5): 218-225.

E

Ebbutt D (1985) Educational Action Research: Some General Concerns and Specific Quibbles. In: R. Burgess (ed) *Issues in Educational Research.* Lewes: Flamer. pp.152-174.

Edmondson A C (1996) Three Faces of Eden: the persistence of competing theories and multiple diagnoses in organizational intervention research. *Human Relations,* 49 (5): 571-595

Ellershaw J, Foster A, Murphy D, Shea T & Overill S (1997) Developing an integrated care pathway for the dying patient. *European Journal of Palliative Care,* 4 (6): 203-207.

Ellershaw J, Smith C, Overill S, Walker S E & Aldridge J (2001) Care of the dying: setting standards for symptom control in the last 48 hours of life. *Journal of Pain and Symptom Management,* 21 (1): 12-17.

Ellershaw J & Coackley A (2002) An integrated care pathway for the dying. *Geriatric Medicine,* April, 45-49

Ellershaw J & Wilkinson S (2003) *Care of the dying: a pathway to excellence.* Oxford: Oxford University Press.

Emanuel L L (2004) Palliative Care I: Providing Care (editorial). *Clinics of Geriatric Medicine*, 20: xi-xiii.

Emanuel E J & Emanuel L L (1998) The promise of a good death. *Lancet,* 351 (suppl.2): 21-29.

Emery F E & Trist E L (1965) The Causal Texture of Organizational Environments. *Human Relations,* 18: 21-32.

Enes S P, Lucas C F, Aberdein N & Lucioni J (2004) Discharging patients from hospice to nursing home: a retrospective case note review. *International Journal of Palliative Nursing,* 10 (3): 124-30.

Engle V F (1998) Care of the Living, Care of the Dying: reconceptualizing nursing home care. *Journal of the American Geriatric Society*, 46: 1172-1174.

Engle V F, Graney M J & Chan A (2001) Accuracy and bias of licensed practical nurse and nursing assistant ratings of nursing home residents' pain. *The Journals of Gerontology Series A: biological sciences and medical sciences,* 56 (7): M397-399.

Ersek et al (2003) The challenges and opportunities in providing end-of-life care in nursing homes. *Journal of Palliative Medicine,* 6 (1): 45-57.

Eve A & Higginson I J (2000) Minimum dataset activity for hospice and hospital palliative care services in the UK 1997/1998. *Palliative Medicine,* 14: 395-404.

Exton-Smith A N (1961) Terminal Illness in the Aged. *The Lancet,* August 5: 305-308.

F

Fairtlough G H (1991) Habermas' concept of "lifeworld". *Systems Practice,* 4 (6): 547-563.

Fals Borda O (2001) Participatory (Action) Research in Social Theory: Origins and Challenges, in: P Reason & H Bradbury (eds) *Handbook of Action Research.* London: Sage Publications. pp.27-37.

Fay B S (1987) *Critical Social Science: liberation and its limits.* Cambridge: Polity Press.

Fealy G M (1999) The theory-practice relationship in nursing: the practitioners' perspective. *Journal of Advanced Nursing,* 30 (1): 74-82.

Ferrell B A (1995) Pain evaluation and management in the nursing home. *Annals of Internal Medicine,* 123 (9): 681-687

Ferrell B A, Ferrell B R & Rivera L (1995) Pain in cognitive impaired nursing home patients. *Journal of Pain and Symptom Management,* 10: 591-598

Field M J, Cassel CK (Eds) (1997) *Approaching Death: improving care at the end of life.* Washington, DC: National Academy Press.

Fisher R, Ross M & MacLean M (2000) *A Guide to End-of-Life Care for Seniors.* Ottawa: University of Toronto and University of Ottawa.

Flaherty (2001) 'Who's taking your 5th vital sign?' (guest editorial) *The Journals of Gerontology Series A: biological sciences and medical sciences,* 56: M397-399.

Flaming D (2000) Improve Care and Comfort: Use the Label "Dying". *Journal of Palliative Care,* 16 (2): 30-36.

Flick U (2001) *An Introduction to Qualitative Research* (2nd ed.). London: Sage Publications.

Flood R & Jackson M C (1991) *Creative Problem Solving.* Chichester: Wiley.

Forbes S (2001) This is Heaven's Waiting Room – End of Life in One Nursing Home *Journal of Gerontological Nursing,* 27 (11): 37-45.

Forbes S, Bern-King M & Gessert C (2000) End-of-life Decision-Making for Nursing Home Residents with Dementia. *Journal of Nursing Scholarship,* Third Quarter: 251-258.

Forbes-Thompson & Gesert (2005) End-of-life in nursing homes: connections between structure, process and outcomes. *Journal of Palliative Medicine,* 8 (3): 545-555.

Fowell A, Finlay I, Johnstone R & Minto L (2002) The Welsh Collaborative Care Pathway Project: implementing an integrated care pathway for the dying patient in Wales. *Journal of Integrated Care Pathways,* 6: 59-62.

Frampton M (2003) Experience assessment and management of pain in people with dementia. *Age & Ageing,* 32 (3): 248-251.

Fraser D (2000) *QSR NVivo Reference Guide* (3rd ed.) Australia: QSR International Pty Ltd.

Freshwater D & Rolfe (2001) Critical reflexivity: a politically and ethically engaged method for nursing. *NTresearch,* 6 (1): 526-537.

Freire P (1970) *Pedagogy of the Oppressed.* New York: Seabury Press.

Froggatt K (2000a) *Palliative care education in nursing homes.* Macmillan Cancer Relief, London.

Froggatt K (2000b) Evaluating a palliative care education project in nursing homes. *International Journal of Palliative Nursing,* 6 (3): 140-146.

Froggatt K (2001a) Life and death in English nursing homes: sequestration or transition? *Ageing & Society*, 21: 319-332.

Froggatt K (2001b) Palliative Care in Nursing Homes: where next? *Palliative Medicine*, 15: 42-48.

Froggatt K (2004) *Palliative Care in Care Homes for Older People.* National Council for Palliative Care, London.

Froggatt K, Hasnip J & Smith P (2000) The challenges of end of life care. *Elderly Care*, 12 (2): 11-13

Froggatt K & Hoult L (2001) Developing palliative care practice in nursing and residential care homes: the role of the clinical nurse specialist. *Journal of Clinical Nursing*, 11 (6): 802-808.

G

Glaser B & Strauss A (1965) *Awareness of Dying.* Chicago: Aldine Publishing.

Gadamer H G (1975) *Truth and Method.* New York: Continuum.

Garbett R & McCormack B (2002) A concept analysis of practice development. *NTresearch*, 7 (2): 87-100.

Gibbs G (1995) Nurses in private nursing homes: a study of their knowledge and attitudes to pain management in palliative care. *Palliative Medicine*, 9 (3): 245-253.

Gibbs G (1988) *Learning by Doing: A guide to teaching and learning methods.* Oxford: Further Education Unit, Oxford Polytechnic.

Glaser B G & Strauss A L (1965) *Awareness of Dying*. Chicago: Aldine Pub. Co.

Glendinning C, Jacobs S, Alborz A & Hann M (2002) A survey of access to medical services in nursing and residential homes in England. *British Journal of General Practice*, 52: 545-548.

Gold R (1958) Roles in sociological field observations. *Social Forces*, 36: 217-223.

Graham H & Livesley B (1983) Dying as a diagnosis: difficulties of communication and management of elderly patients. *The Lancet*, September 17: 670-772.

Green K (2002) Defining the field of literature in action research: a personal approach, in: C. Day, J. Elliott, B. Smekh & R. Winter (eds) *Theory and practice in action research: some international perspectives.* Oxford: Symposium Books. pp.121-140.

Greenbaum T L (1998) *The Handbook of Focus Group Research* (2^{nd} ed.). London: Sage Publications Ltd.

Greenwood J (1994) Action research: a few details, a caution and something new. *Journal of Advanced Nursing,* 20: 13-18.

Greenwood D J & Levin M (1998) *Introduction to Action Research.* London: Sage Publications.

Groom L, Avery A J, Boot D, O'Neil C, Thornhill K, Brown K & Jones R (2000) The impact of nursing home patients on general practitioners' workload. *British Journal of General Practice,* 50: 473-476.

Gummesson E (2000) *Quality Methods in Management Research.* Sage Publications Inc: Thousand Oaks, CA.

Guba, E. & Lincoln, Y. 1994, Competing Paradigms in Qualitative Research, in: N. K. Denzin & Y. S. Lincoln (eds.), *Handbook of Qualitative Research.* London: Sage Publications. pp. 105-117.

Gubrium J F (1975) *Living and dying at Murray Manor.* New York: St Martin's Press.

Gunz J (1996) Jacob L. Moreno and the Origins of Action Research. *Educational Action Research,* 4 (1): 145-148.

Gustavsen B (2003) New forms of knowledge production and the role of action research. *Action Research,* 1 (2): 153-164.

H

Habermas J (1972) *Knowledge and Human Interest* (translated by Jeremy J. Shapiro). London: Heinemann Educational.

Habermas J (1974) *Theory and Practice* (translated by John Viertal). London: Heinemann.

Habermas J (1984) *The Theory of Communicative Action. Vol. I: Reason and the rationalization of society* (translated by Thomas McCarthy). London: Heinemann.

Habermas J (1987a) *The Theory of Communicative Action. Vol. II: Lifeworld and System: a critique of functionalist reason.* (translated by Thomas McCarthy). Polity Press: Cambridge

Habermas J (1987b) *The Philosophical Discourse of Modernity.* (translated by Frederick G. Lawrence). Cambridge, MA: The MIT Press.

Hall P, Schroder C & Weaver L (2002) The last 48 hours of life in long-term care: a focused chart audit. *Journal of the American Geriatric Society,* 50 (3): 501-6.

Hanson L, Henderson M & Menon M (2002) As Individual as Death Itself: a focus group study of terminal care in nursing homes. *Journal of Palliative Medicine,* 5 (1): 117-125.

Happ M B, Capezuti E, Strumpf N E, Wagner L, Cunningham S, Evans L & Maislin G (2002) Advance Care Planning for End-of-Life Care for Hospitalized Nursing Home Residents. *Journal of the American Geriatric Society,* 50: 829-835.

Haraldsdottir E (2005) *Constraints of the ordinary: caring for dying patients in a hospice in Scotland.* PhD thesis presented at: *Enlightened Holistic Care: from research to practice through reflection.* Reykjavik, Iceland. May 30 – June 1, 2005.

Hart E & Bond M (1995) *Action research for health and social care: a guide to practice.* Buckingham: Open University Press.

Hart E & Bond M (1996) Making sense of action research through the use of a typology. *Journal of Advanced Nursing,* 23: 152-159.

Hayes N & Martin F (2004) Supporting care homes: the older people's specialist nurse. *British Journal of Nursing,* 13 (21): 1250-1257.

Heath H (1998) Reflection and patterns of knowing in nursing. *Journal of Advanced Nursing,* 27: 1054-1059.

Held (1980) *Introduction to Critical Theory: Horkheimer to Habermas.* Polity Press: Cambridge.

Heron J (1981) Philosophical basis for a new paradigm, in: P. Reason & J. Rowan (eds.), *Human Inquiry: a sourcebook of new paradigm research.* Chichester: John Wiley & Sons. pp. 19-35.

Heron J (1996) *Co-operative Inquiry: research into the human condition.* London: Sage Publications.

Hockey J (1990) *Experiences of death: an anthropological account.* Edinburgh: Edinburgh University Press.

Hockley J M (1993) 'Rehabilitation in palliative care – are we asking the impossible?' *Palliative Medicine,* 7: 9-15 (suppl)

Hockley J. (2002) Organizational structures for enhancing standards of palliative care, in: J Hockley & D Clark (eds) *Palliative Care for Older People in Care Homes.* Buckingham: Open University Press. pp. 165-181.

Hockley J, Dewar B, Watson J (2004) *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.* Available from: www.stcolumbashospice.org.uk/professional

Holmes C & Warelow P (2000) Nursing as normative praxis. *Nursing Inquiry,* 7 (3): 175-181.

Holter I M (1993) Critical action research and the changing role of nurse executives: a case study. Unpublished PhD thesis, University of Rhode Island.

Holter I & Schwartz-Barcott D (1993) Action research: what is it? How has it been used and how can it be used in nursing? *Journal of Advanced Nursing,* 18: 298-304.

Hope K W & Waterman H A (2003) Praiseworthy pragmatism? Validity and action research. *Journal of Advanced Nursing,* 44 (2): 120-127.

Hopkinson J (2002) The hidden benefit: the supportive function of the nursing handover for qualified nurses caring for dying people in hospital. *Journal of Clinical Nursing,* 11 (2): 2168-175

Hotchkiss R (1997) Integrated Care Pathways. *NTResearch,* 2 (1): 30-37.

Howarth G (1998) 'Just live for today'. Living, caring, ageing and dying. *Ageing and Society,* 18: 673-689

Hughes J C, Robinson L & Volicer L (2005) Specialist palliative care in dementia. *British Journal of Medicine,* 330: 57-58.

Hunsaker-Hawkins A & Ballard J A (1995) *Time to Go: three plays on death and dying with commentary on end-of-life issues.* Philadelphia: University of Pennsylvania Press.

Hurst D (2003) *Selecting and Applying Methods for Estimating the Size and Mix of Nursing Teams.* Leeds University: Nuffield Institute for Health.

Hyde A & Roche-Reid B (2004) Midwifery practice and the crisis of modernity: implications for the role of the midwife. *Social Science and Medicine*, 58 (12): 2613-2623.

Hyde A & Murray M (2005) Nurses' experiences of distance education programmes. *Journal of Advanced Nursing*, 49 (1): 87-95.

Hyder A A & Wali S A (2006) Informed consent and collaborative research: perspectives from the developing world. *Developing World Bioethics*, 6 (1): 33-40.

J

Jacobs S (2003) Addressing the problems associated with general practitioners' workload in nursing and residential homes: findings from a qualitative study. *British Journal of General Practice,* 53: 113-119.

Johns C (1998) Opening the Doors of Perception, in: C Johns & D Freshwater (eds) *Transforming Nursing through Reflective Practice.* Oxford: Blackwell Science. pp.1-20.

Johns C (2000) *Becoming a Reflective Practitioner.* Oxford: Blackwell Science.

Johns C & Freshwater D (1998) *Transforming Nursing through Reflective Practice.* Oxford: Blackwell Science.

K

Kapp (2003) Legal anxieties and end-of-life care in nursing homes. *Issues in Law & Medicine,* 19 (2): 111-134.

Katz J, Komaromy C & Sidell M (1999) Understanding palliative care in residential and nursing homes. *International Journal of Palliative Nursing,* 5: 58-64.

Katz J, Sidell M & Komaromy C (2000) Death in homes: bereavement needs of residents, relatives and staff. *International Journal of Palliative Nursing,* 6 (6): 274-279.

Katz J S & Peace S (2003) *End of life in care homes.* Oxford: Oxford University Press.

Kayser-Jones J (2002) The experience of dying: an ethnographic nursing home study. *Gerontologist,* 42 (3): 11-19.

Kayser-Jones J, Schell E, Lyons W, Kris A E, Chan J & Beard R L (2003) Factors that influence end-of-life care in nursing homes: the physical environment, inadequate staffing, and lack of supervision. *Gerontologist,* 43 (2): 76-84.

Kayser-Jones J, Chan J & Kris A (2005) A model long-term care hospice unit: care, community and compassion. *Geriatric Nursing,* 26 (1): 16-20.

Kearney M (1992) Palliative medicine: just another specialty? *Palliative Medicine,* 6 (1): 39-46.

Kelly D (2003) A commentary on 'an integrated care pathway for the last two days of life'. *International Journal of Palliative Nursing,* 9 (1): 39.

Kelly D & Simpson S (2001) Action research in action: reflections on a project to introduce Clinical Practice Facilitators to an acute hospital setting. *Journal of Advanced Nursing,* 33 (5): 652-659.

Kemmis S (1985) Action Research and the Politics of Reflection, in: D Boud, R Keogh & D Walker (eds) *Reflection: turning experience into learning.* London: Kogan Page. pp.139-163.

Kemmis S (2001) Exploring the Relevance of Critical Theory for Action Research: Emancipatory Action Research in the Footsteps of Jurgen Habermas. In: P Reason & H Bradbury's *Handbook of Action Research: participator inquiry and practice.* London: Sage Publications. pp.91-102.

Kemmis S & McTaggart R (1988) *The Action Research Planner.* Deakin: Deakin University Press.

Kim H S (1999) Critical reflective inquiry for knowledge development in nursing practice. *Journal of Advanced Nursing,* 29 (5): 1205-1212.

Kinder C & Ellershaw J (2003) How to use the Liverpool Care Pathway for the Dying Patient? in: J Ellershaw & S Wilkinson (eds) *Care of the dying: a pathway to excellence.* Oxford: Oxford University Press. pp.11-41.

Kincheloe J L & McLaren P L (1994) Rethinking critical theory and qualitative research, in: N K Denzin & Y S Lincoln (eds), *Handbook of Qualitative Research.* London: Sage Publications. pp.138-157.

Kitchiner D, Davidson C & Bundred P (1996) Integrated Care Pathways: effective tools for continuous evaluation of clinical practice. *Journal of Evaluation in Clinical Practice,* 2 (1): 65-69.

Kitson A, Harvey G & McCormack B (1998) Enabling the implementation of evidence based practice: a conceptual framework. *Quality in Health Care,* 7: 149-158.

Kitwood T M (1997) *Dementia reconsidered: the person comes first.* Milton Keynes: Open University Press.

Kitzinger J (1994) The methodology of focus groups: the importance of interaction between research participants. *Sociology of Health and Illness,* 16 (1): 103-121.

Kitzinger J (1996) Introducing Focus Groups, in: N Mays & C Pope (eds) *Qualitative Research in Health Care.* London: British Medical Journal Publishing Groups.

Komaromy C, Sidell M & Katz J (2000) The quality of terminal care in residential and nursing homes. *International Journal of Palliative Nursing,* 6 (4): 192-200.

Kristjanson L J, Walton J & Toye C (2005) End-of-life challenges in residential aged care facilities: a case for a palliative approach to care. *International Journal of Palliative Nursing,* 11 (3): 127-129.

Kvale S (1996) *Interviews: an introduction to qualitative research interviewing.* London: Sage Publications.

L

Ladkin D (2004) Action Research in Practice: what the books don't tell you, in: C Seale, G Gobo, J F Gubrium & D Silverman (eds) *Qualitative Research Practice.* London: Sage Publications. pp536-548.

Laing & Buisson (2002) *Care of the elderly people: market survey 2002* (eleventh ed.). London: Laing and Buisson.

Lane P, McKenna H, Ryan A & Fleming P (2001) Focus group methodology. *Nurse Researcher,* 8 (3): 45-49.

Lauri S (1982) Development of the nursing process through action research. *Journal of Advanced Nursing,* 7 (4): 301-307.

Leichtentritt R D & Rettig K D (2000) The good death: reaching an inductive understanding. *Omega,* 41 (3):221-248.

Lewin K (1948) *Resolving Social Conflicts.* New York: Harper.

Lewin K (1952) *Field Theory in Social Science.* London: Tavistock.

Leyland J Y (2000) Death and dying: management of patients with end-stage disease. *Clinics of Geriatric Medicine,* 16 (4): 875-894.

LHB (1999) Lothian Health Board. Deaconess House, The Pleasance, Edinburgh EH8.

Lloyd-Williams M & Payne S (2002) Can multidisciplinary guidelines improve the palliation of symptoms in the terminal phase of dementia? *International Journal of Palliative Nursing,* 8 (8): 370-375.

Lofland J & Lofland L H (1995) *Analyzing Social Settings: a guide to qualitative observation and analysis* (3rd ed.). London: International Thomson Publishing Europe.

Lothian Palliative Care Guidelines (2002) Available from: http://www.scan.scot.nhs.uk

Lynn J & Adamson DM (2003) *Living well at the end of life: adapting health care to serious chronic illness in old age.* Downloaded 16/09/03 from www.medicaring.org/whitepaper/

Lynn J & Goldstein N E (2003) Advance Care Planning for Fatal Chronic Illness: Avoiding Commonplace Errors and Unwarranted Suffering. *Annals of Internal Medicine,* 138: 812-818.

M

Macleod-Clark J, Maben J & Jones K (1996) The use of focus group interviews in nursing research: issues and challenges. *NTresearch,* 1 (2): 143-153.

Macmillan Cancer Relief (2004) *Foundations in palliative care: a programmed of facilitated learning for care-home staff.* Available from: www.macmillan.org.uk

McCue J D (1995) The Naturalness of Dying. *Journal of the American Medical Association,* 273 (13): 1039-1043.

McCormack B, Manley K, Kitson A, Titchen A Harvey G (1999) Towards practice development – a vision in reality or a reality without vision? *Journal of Nursing Management,* 7 (5), 255-264.

McCormack B, Kitson A, Harvey G, Rycroft-Malone J, Titchen A & Seers K (2001) Getting evidence into practice: the meaning of 'context'. *Journal of Advanced Nursing,* 38 (1), 94-104.

McCue J D (1995) The Naturalness of Dying. *Journal of the American Medical Association,* 273 (13): 1039-1043.

McGill I & Beaty L (1995) *Action Learning* (2nd ed). London: Kogan Page.

McKernan J (1991) *Curriculum Action Research: a handbook of methods and resources for the reflective practitioner.* London: Kogan Page Ltd.

McNiff J & Whitehead J (2002) *Action Research: Principles and Practice* (2nd ed). London: RoutledgeFalmer.

McTaggart R (1996) Issues for Participatory Action Researchers, in: O Zuber-Skerritt (ed.) *New Directions in Action Research.* London: RoutledgeFalmer. pp.243-255.

Maddocks I & Parker D (2001) Palliative care in nursing homes, in: J Addington-Hall & I Higginson (eds) *Palliative Care for Non-Cancer Patients.* Oxford: Oxford University Press. pp.147-157.

Mania E & Street A (2001) Rethinking ethnography: reconstructuring nursing relationships. *Journal of Advanced Nursing,* 33 (2): 234-242.

Manley K (1997) A conceptual framework for advanced practice: an action research project operationalizing an advanced practitioner/consultant nurse role. *Journal of Clinical Nursing,* 6 (3): 179-190.

Manley K (2000) Organisational culture and consultant nurse outcomes: Part 1: Organisational culture. *Nursing Standard,* 30 (14): 34-38.

Manley K (2001) *Consultant nurse: concept, processes, outcomes.* Unpublished doctoral thesis. London: University of Manchester/ RCN Institute.

Marx K (1845) Theses on Feuerbach. *Marx/Engel Internet Archive.* Accessed December 2005: http://www.marxists.org/archive/marx/works/1845/theses/theses.htm

Mason J (1996) *Qualitative Researching.* London: Sage Publications.

Melvin M (1951) Advancing Years. *University of Leeds Medical Magazine,* No.2: 57-60.

Menzies I (1960) Social systems as a defence against anxiety. *Human Relations,* 13 (2): 95-121.

Meyer J (1995) *Lay Participation in Care in a Hospital Setting: An action research study.* PhD thesis, King's College London, University of London.

Meyer J (2000) Using qualitative methods in health related action research. *British Medical Journal,* 320: 178-181.

Meyer J & Batehup L (1997) Action research in health-care practice: Nature, present concerns and future possibilities. *NTresearch,* 2 (3): 175-184.

Meyer J, Spilsbury K & Prieto J (1999) Comparison of findings from a single case in relation to those from a systematic review of action research. *Nurse Researcher,* 7 (2): 37-59.

Mezirow J (1991) *Transformative Dimensions of Adult Learning.* San Francisco: Jossey-Bass.

Miles M B & Huberman A M (1994) *Qualitative Data Analysis: a sourcebook of new methods.* London: Sage Publications.

Miller C, Scholes J & Freeman P (1998) *Evaluation of the 'assisting clinical effectiveness programme'.* Centre for Nursing and Midwifery Research, Brighton: University of Brighton.

Mirando S, Davies P D & Lipp A (2005) Introducing an integrated care pathway for the last days of life. *Palliative Medicine,* 19 (1): 33-39.

Mishler E (1984) *The Discourse of Medicine: dialectics of medical interviews.* Norwood, NJ: Ablex.

Miskella C & Avis M (1998) Care of the dying person in the nursing home: exploring the care assistants' contribution. *European Journal of Oncology Nursing,* 2 (2): 80-86.

Mitchell S L, Teno J M, Roy J, Kabumoto G & Mor V (2003) Clinical and organizational factors associated with feeding tube use among nursing home residents with advanced cognitive impairment. *Journal of the American Medical Association,* 290 (1): 73-80.

Mitchell S L, Morris J N, Park P S & Fries B E (2004a) Terminal Care for Persons with Advanced Dementia in the Nursing Home and Home Care Settings. *Journal of Palliative Medicine,* 7 (6): 808-816.

Mitchell S L, Kiely D K & Hamel M B (2004b) Dying with advanced dementia in the nursing home. *Archives of Internal Medicine,* 164 (3): 321-326.

Mohammed A M, Rathbone A, Myers P, Patel D, Onions H & Stevens A (2004) An investigation into general practitioners associated with high patient mortality flagged up through the Shipman inquiry: retrospective analysis of routine data. *British Medical Journal,* 328 (7454): 1454-73.

Morgan D L (1993) *Successful Focus Groups: advancing the state of the art.* London: Sage Publications.

Morrison R S & Siu A L (2000) Survival in end-stage dementia following acute illness. *Journal of the American Medical Association,* 284: 47-52.

Moss M S, Moss A Z, Rubinstein R L & Black H K (2003) The metaphor of 'family' in staff communication about dying and death. *Journals of Gerontology Series B: Psychological Sciences and Social Sciences,* 58(5) S290-6.

Mount B (1989) First International conference on Palliative Care of the Elderly, in: R. Fisher, M. Ross and M. MacLean (eds) (2000) *A guide to End-of-Life Care for Seniors.* Canada: University of Toronto and University of Ottawa. p.97.

Munday D F, Johnson S A & Griffiths F E (2003) Complexity theory and palliative care. *Palliative Medicine,* 17 (4): 308-9.

Murphy D (2003) The education strategy to implement the Liverpool Care Pathway for the Ding Patient (LCP), in: J Ellershaw & S Wilkinson (eds) *Care of the dying: a pathway to excellence.* Oxford: Oxford University Press. pp.106-120.

N

National Health Service & Community Care Act 1990 (c.19) Stationery Office Ltd: London. Available online: http://www.opsi.gov.uk/acts/acts1990

National Statistics Online 2004. Accessed on 5th October 2005. http://www.statistics.gov.uk

NCHSPCS (1997) *Changing Gear: Guidelines for Managing the Last Days of Life — The Research Evidence.* Clinical Guidelines Working Party. National Council for Hospice and Specialist Palliative Care Services, London.

NCPC (2005) *Improving palliative care provision for older people in care homes.* The National Council for Palliative Care: London.

Netten A, Darton R & Williams J (2003) Nursing home closures: effects on capacity and reasons for closure. *Age and Ageing,* 32: 332-337.

Nolan M & Grant G (1993) Action research and quality of care: a mechanism for agreeing basic values as a precursor to change. *Journal of Advanced Nursing,* Vol 18: 305-311.

O

Odell A (1996) Communication theory and the shift handover report. *British Journal of Nursing,* 5 (21): 1323–1326.

Oja S N & Smulyan L (1989) *Collaborative action research: A developmental approach.* Philadelphia: The Falmer Press.

Oliver D P, Porock D & Zweig S (2004) End of life care in U.S. nursing homes: a review of the evidence. *Journal of the American Medical Directors Association,* 5 (3): 147-155.

Overill S (1998) A practical guide to care pathways. *Journal of Integrated Care*, 2(3): 93-98.

Overill S (2003) The development, role and integration of integrated care pathways in modern day health care, in: J Ellershaw & S Wilkinson (eds) *Care of the dying: a pathway to excellence.* Oxford: Oxford University Press. pp.1-10.

P

Palmer A, Burns S & Bulman C (1994) *Reflective Practice in Nursing: the growth of the Professional Practitioner.* London: Blackwell Scientific Publications.

Park P (2001) Knowledge and Participatory Research, in: P. Reason & H. Bradbury (eds.) *Handbook of Action Research: Participative Inquiry & Practice*. London: Sage Publication, pp. 81-90.

Parker D & McLeod A (2002) Assessment of need in care homes, in: J Hockley & D Clark (eds.) *Palliative Care for Older People in Care Homes.* Buckingham: Open University Press. pp.34-51.

Parker-Oliver D (2002) Hospice experience and perceptions in nursing homes. *Journal of Palliative Medicine,* 5 (5): 713-720.

Parahoo K (1997) *Nursing research: principles, process and issues.* Basingstoke: Macmillan.

Pattison (1977) *The Experience of Dying.* Englewood Cliffs, NJ: Prentice Hall.

Paton R A & McCalman J (2000) *Change Management: a guide to effective implementation* (2nd ed.), London: Sage Publications.

Payne S & Langley-Evans A (1996) Perception of a 'good' death: a comparative study of the views of hospice staff and patients. *Palliative Medicine,* 10: 307-312.

Payne S, Seymour J & Ingleton C (2004) Introduction, in: S Payne, J Seymour & C Ingleton (eds.) *Palliative Care Nursing: principles and evidence for practice.* Berkshire: Open University Press. pp.1-12.

Peace S, Kellaher L & Willcocks D (1997) *Re-evaluating residential care.* Buckingham: Open University Press.

Pearson M & Smith D (1985) Debriefing in Experience-based Learning, in: D. Boud, R. Keogh & D. Walker (eds.), *Reflection: Turning Experiences into Learning.* London: Kogan Page. pp: 69-84.

Pell & Williams (1999) Do nursing home residents make greater demands on GPs? A prospective, comparative study. *British Journal of General Practice*, 49 (44) 527-530.

Penney W & Warelow P J (1999) Understanding the prattle of praxis. *Nursing Inquiry,* 6: 259-268.

Phelps R & Hase S (2002) Complexity and Action Research: exploring the theoretical and methodological connections. *Educational Action Research,* 10 (3): 507-523.

Philp (2003) End-of-life care for older people. *European Journal of Palliative Care,* 10 (4): 151-153.

Plsek P E & Greenhalgh T (2001) The challenge of complexity in health care. *British Medical Journal,* 323: 625-628.

Pontin D (1996) The effect of primary nursing on the quality of nursing care: an action research study of nursing development work. Unpublished PhD. Thesis, University of Manchester.

Porter S (1998) *Social Theory and Nursing Practice*. London: Macmillan.

Prail D (2000) Who are we here for? (editorial) *Palliative Medicine,* 14: 91-92.

R

Raffery A M, Allcock N & Lathlean J (1996) The theory/practice 'gap': taking issue with the issue. *Journal of Advanced Nursing,* 23 (4): 685-691

Rasmussen D M (1990) *Reading Habermas.* Oxford: Basil Blackwell Ltd.

RCN (2002) *Fostering a culture of effectiveness through practice development.* Royal College of Nursing Institute Summer School, Scotland.

RCP, RCN, BGS (2000) *The health and care of older people in care homes: a comprehensive interdisciplinary approach.* A report of a joint working party. Royal College of Physicians of London, London.

Reason P (1988) *Human Inquiry in Action: developments in new paradigm research.* London: Sage Publications.

Reason P & Rowan J (1981) (eds) *Human Inquiry: a sourcebook of new paradigm research.* Chichester: John Wiley.

Reason P & Bradbury H (2001) Introduction: Inquiry and Participation in Search of a World Worthy of Human Aspiration, in: P. Reason & H. Bradbury (eds) *Handbook of*

Action Research: participative inquiry and practice. London: Sage Publications, pp.1-14.

Redfern S, Hannan S, Norman I & Martin F (2002) Work satisfaction, stress, quality of care and morale of older people in a nursing home. *Health and Social Care in the Community,* 10 (6): 512-7.

Redfern S & Christian S (2003) Achieving change in health care practice. *Journal of Evaluation in Clinical Practice,* 9 (2): 225-238.

Redfern S & Norman I (1999) Quality of nursing care perceived by patients and their nurses: an application of the critical incident technique. Part 2. *Journal of Clinical Nursing,* 8: 414-421.

Reed and Payton (1997) Focus groups: issues of analysis and interpretation. *Journal of Advanced Nursing,* 26: 765-771.

Reed J, Cook G & Burridge C (2002) Loss and Change, in: J Hockley & . Clark (eds.) *Palliative Care for Older People in Care Homes.* Buckingham: Open University Press. pp.52-65.

Rees G, Huby G, McDade L, McKechnie L (2004) Joint working in community mental health teams: implementation of an integrated care pathway. *Health and Social Care in the Community,* 12 (6): 527-536.

Reynolds K. Henderson M, Schulman A & Hanson L C (2002) Needs of the Dying in Nursing Homes. *Journal of Palliative Medicine,* 5 (6): 895-901.

Rice K N, Coleman E A, Fish R, Levy C, Kutner J S (2005) Factors influencing models of end-of-life care in nursing homes: results of a survey of nursing home administrators. *Journal of Palliative Medicine,* 8 (3): 477-479.

Riley K (1998) Paving the Way. *Health Service Journal,* 108: 30-31.

Robinson N (1999) The use of focus group methodology – with selected examples from sexual health research. *Journal of Advanced Nursing,* 29 (4): 905-913.

Robottom, I & Colquhoun, D (1993) The politics of method in public health research, in: R. Colquhoun & A. Kellehear (eds.), *Health Research in Practice: Political, Ethical and Methodological Issues.* London: Chapham and Hall, pp. 47-64.

Rolfe G (1993) Closing the theory-practice gap: a model of nursing praxis. *Journal of Clinical Nursing,* 2: 173-177.

Rolfe G (1997) Nursing praxis: a zealot responds. *Journal of Advanced Nursing,* 25: 426-427.

Rolfe G, Freshwater D & Jasper M (2001) *Critical reflection for nursing and the helping professions: a user's guide.* London: Palgrave Macmillan

Rowan J (2001) The Humanistic Approach to Action Research, in: P Reason & H Bradbury (eds) *Handbook of Action Research.* London: Sage Publications. pp.114-123.

Rowan J & Reason P (eds) (1981) *Human Inquiry: A sourcebook of new paradigm research.* Chichester, UK: John Wiley.

Rummans T A, Bostwick J M & Clark M M (2000) Maintaining quality of life at the end of life. (Mayo Clinic Cancer Center Quality of Life Working Group) *Mayo Clinic Proceedings,* 75 (12): 1305-1310.

Ruth N (2002) Insider-Outsider Perspectives: Commentary. *Nurse Researcher,* 9 (4): 4-6.

S

Sandow S (1979) Action research and evaluation: can research and practice be successfully combined? *Child: health, care and development,* 5 (3): 211-223.

Saunders C (1987) What's in a name? *Palliative Medicine,* 1: 57-61.

Scambler G (1987) Habermas and the power of medical expertise, in G. Scambler (ed.) *Sociological Theory and Medical Sociology.* London: Tavistock.

Schon D (1987) *Educating the Reflective Practitioner: toward a new design for teaching and learning in the professions.* London: Jossey-Bass.

Scottish Executive (2001) *National Care Standards – care homes for older people.* Stationery Office Bookshop, Edinburgh.

Scottish Executive (2003) Care Homes, Scotland – Statistics Release. A Scottish Executive National Statistics Publication, available: www.scotland.gov.uk/stats/bulletins

Senge P (1990) *The Fifth Discipline.* London: Random House Business Books.

Sepulveda C, Marlin A, Yoshida T & Ullrich A (2002) Palliative care: the World Health Organization's global perspective. *Journal of Pain and Symptom Management,* 24 (2): 91-96.

Seymour J (2003) Technology and 'natural death': a study of older people. *Zeitschrift für Gerontologie und Geriatrie,* 36 (5): 339-346.

Shalev A Y, Peri T, Rogel-Fuchs Y, Ursano R J & Marlowe D (1998) *Military Medicine,* 163 (7): 494-498.

Shemmings Y (1996) *Death, dying and residential care.* Aldershot: Avebury.

Shipman Inquiry (2005) Available from: www.the-shipman-inquiry.org.uk

Sidell N, Katz J & Komaromy C (1997) *Dying in Nursing and Residential Homes for Older People: examining the case for palliative care.* Report for the Department of Health. Milton Keynes: Open University.

Singer P A, Martin D K & Kelner M (1999) Quality End-of-Life Care: patients' perspectives. *Journal of the American Medical Association*, 281 (2): 163-168.

Smith G (1989) Resistance to change in geriatric care. *International Journal of Nursing Studies*, 23 (1): 61-70.

Spaul M W J (1995) Critical Systems Thinking and 'New Social Movements': A Perspective from the Theory of Communicative Action'. *Systems Practice,* 9 (4): 317-322.

SPPC (2005) *National Palliative Care Practice Statements for Care Homes in Scotland: a consultation document.* [in press] Scottish Partnership for Palliative Care, Edinburgh.

Spradley, J P (1980) *Participant Observation.* New York: Holt, Rinehart & Winston.

Stephenson J (1999) Veterans' pain a vital sign. *Journal of the American Medical Association,* 281 (11): 2197-2198.

Stoter D J (1997) *Staff Support in Health Care*. Oxford: Blackwell Science.

Street A (1995) *Nursing Replay: researching nursing culture together.* Edinburgh: Churchill Livingstone.

Stringer E T (1996) *Action Research: a handbook for practitioners*. Thousand Oaks, CA: Sage Publications.

Strumpf N E, Tuch H, Stillman D, Parrish P & Morrison N (2004) Implementing Palliative Care in the Nursing Home. *Annals of Long-Term Care,* 12 (11): 35-41.

Sullivan A (2005) It's a wonderful life. *The Sunday Times: News Review,* Aug. 14: 1-2.

Swagerty D J, Lee R H, Smith B & Taunton R L (2005) The context for nursing home resident care: the role of leaders in developing strategies. *Journal of Gerontological Nursing,* 31 (2): 40-48.

T

Taylor C & White S (2000) *Practising Reflexivity in Health and Welfare: making knowledge.* Buckingham: Open University Press.

Teno J M (2003) Now is the time to embrace nursing homes as a place of care for dying persons. *Journal of Palliative Medicine,* 6 (2): 293-296.

Teno J M, Weitzen S, Wetle T & Mor V (2001) Persistent pain in nursing home residents. *Journal of the American Medical Association,* 285 (16): 2081.

Tewdwr-Jones M & Allmendinger P (1998) Deconstructing communicative rationality: a critique of Habermasian collaborative planning. *Environment and Planning*, 30:1975-1989.

The National Palliative Care Program (2004) *Guidelines for a Palliative Approach in Residential Aged Care.* Prepared by: Edith Cowan University. Downloaded from: http://www.health.gov.au/internet/wcms/publishing.nsf/Content/palliativecare-pubs-workf-guide.htm

Titchen A (1995) Issues of validity in action research. *Nurse Researcher,* 2 (3): 38-48.

Titchen A (2000) *Professional Craft Knowledge in Patient-centred Nursing and the Facilitation of its Development.* D.Phil thesis. Oxford: Ashdale Press.

Titchen & Binnie (1993a) The 'double act': co-action researcher roles in an acute hospital setting, in A Titchen & A Binnie (eds) *Changing Nursing Practice Through Action Research,* Chapter 3, Report No. 6 National Institute for Nursing Centre for Practice Development and Research, Oxford.

Titchen A & Binnie A (1993b) Research partnerships: collaborative action research in nursing. *Journal of Advanced Nursing,* 18 (6): 858 – 865.

Titchen A & Binnie A (1994) Action research: a strategy for theory generation and testing. *International Journal of Nursing Studies,* 31 (1): 1-12.

Tolstoy L (1960) *The Death of Ivan Ilyich and other Stories.* London: Penguin Classics.

Torbet W R (2001) The practice of action inquiry, in: P. Reason & H. Bradbury (eds), *Handbook of Action Research: participative inquiry and practice.* London: Sage Publications. p.250-260.

Towell D (1979) A 'social systems' approach to research and change in nursing care. , *Journal of Nursing Studies,* 16 (1): 111-121.

Travis S, Bernard M, Dixon S, McAuley W J, Loving G & McClanahan L (2002) Obstacles to Palliation and End-of-Life Care in a Long-Term Care Facility. *The Gerontologist,* 42: 342-349.

Tuch H, Parrish P & Romer A L (2003) Integrating Palliative Care into Nursing Homes. *Journal of Palliative Medicine,* 6 (2): 297-309.

V

Vallis J & Boyd K (2002) Ethics and end-of-life decision-making, in: J Hockley & D Clark (eds) *Palliative Care for Older People in Care Homes.* Buckingham: Open University Press. pp.120-137.

Vivat B (2004) *The Whole and the Parts: Spiritual Aspects of Care in a West of Scotland Hospice.* PhD thesis: University of Edinburgh.

W

Walker L, Porter M, Gruman C, Michalski M. (1999) Developing individualized care in nursing homes: integrating the views of nurses and certified nurse aides. *Journal of Gerontological Nursing,* 25 (3): 30-5.

Ward C & McCormack B (2000) Creating an adult learning culture through practice development. *Nurse Education Today,* 20: 259-266.

Waterman H (1998) Embracing ambiguities and valuing ourselves: issues of validity in action research. *Journal of Advanced Nursing,* 28 (1): 101-105.

Waterman H, Webb C & Williams A (1995) Parallels and contradictions in the theory and practice of action research and nursing. *Journal of Advanced Nursing,* 22: 779-784.

Waterman H, Tillen D, Dickson R & de Koning R (2001) *Action research: a systematic review and guidance for assessment.* Copies available from: The National Coordinating Centre for Health Technology Assessment, Southampton SO16 7PX. NHSnet: http://nww.hta.hnsweb.nhs.uk

Webb C (1989) Action research: philosophy, methods and personal experiences. *Journal of Advanced Nursing,* 14: 403-410.

Webb G (1996) Becoming Critical of Action Research for Development, in: O Zuber-Skerritt (ed) *New Directions in Action Research.* London: RoutledgeFalmer. pp.137-161.

Webb C, Turton P & Pontin D (1998) Action research: the debate moves on, in: B. Roe & C. Webb (eds) *Research and Development in Clinical Nursing Practice.* London: Whurr Publishers Ltd, pp. 290-311.

Weiner D K & Hanlon J T (2001) Pain in nursing home residents: management strategies. *Drugs & Aging,* 18 (1): 13-29.

White S (1988) *The recent work of Jurgen Habermas: reason, justice and modernity.* Cambridge: Cambridge University Press.

Wicke D, Coppin R & Payne S (2003) Teamworking in nursing homes. *Journal of Advanced Nursing,* 45 (2): 197-204.

Williams E L, Savage S, McDonald P & Groom L (1992) Residents of private nursing homes and their care. *British Journal of General Practice,* 42: 477-481.

Williamson G R & Prosser S (2002) Action research: politics, ethics and participation. *Journal of Advanced Nursing,* 40 (5): 587-593.

Williamson P (1992) Dissemination to use: the management and organisational barriers to the application of health service research findings. *Health Bulletin*, 50 (1): 76-78.

Wilson J (1998) Integrated Care Management. *British Journal of Nursing,* 7 (4): 201-202.

Winter R & Munn-Giddings C (2001) *A Handbook for Action Research in Health and Social Care*. London: Routledge.

Y

Young J & Philp I (2000) Future directions for geriatric medicine. Geriatricians must move with their patients into the community. *British Medical Journal,* 320: 133-134.

Z

Zander K (1992) Critical Pathways, in: M. Minerva Melum & M. Kuchuris Sinioris (eds) *Total Quality Management: the health care pioneers.* American Hospital Publishing: Chicago. pp.305-314.

APPENDICES

APPENDIX 1:	Information Sheet
APPENDIX 2a:	Consent form (focus group/interview)
APPENDIX 2b:	Consent form (management)
APPENDIX 2c:	Consent form (staff)
APPENDIX 3:	Focus group discussion outline
APPENDIX 4a	Semi-structure interview outline (relative)
APPENDIX 4b:	Semi-structure interview outline (professionals)
APPENDIX 5:	Documentary pro-forma
APPENDIX 6:	Contact summary & initial analysis sheet
APPENDIX 7:	Example of feedback report to nursing home manager
APPENDIX 8:	Exploratory phase - evaluation questionnaire
APPENDIX 9:	ICP ‘core’ group action sheet
APPENDIX 10:	ICP – base review
APPENDIX 11:	ICP documentation
APPENDIX 12:	Case scenario for education on ICP documentation
APPENDIX 13a:	Evaluation interview following ICP implementation
APPENDIX 13b:	Evaluation questionnaire following ICP implementation

APPENDIX 1

The 'Bridges Initiative'

INFORMATION SHEET

The 'Bridges Initiative' is an action research project aiming to build bridges between the Hospice and local nursing homes with their associated primary care teams, in order to extend and develop the 'palliative care approach' to elderly dying residents and their families in the nursing home setting.

Action research is not research on other people or for other people, but research with other people. It is very much a collaborative way of researching that will hopefully bring about change during the actual research process. I am a clinical nurse specialist that has had considerable experience in palliative care and been appointed to head up the Bridges Initiative. I plan to collaborate and work with yourself, the nurses and carers in your nursing home specifically in order to extend the 'palliative care approach' to frail and ill residents in a way that is appropriate for nursing home. My time in your nursing home would be for 8-12 months, with a final evaluation being carried out after 12 months. There are three phases to the Bridges Initiative:

An exploratory phase – during which time I will be involved in working alongside nurses/carers and observing the care given to frail and ill residents facing the end of their lives in the nursing home. Involvement through interview with one specific resident and their family will help me understand the physical and psychosocial needs of residents dying in nursing homes. It will also bring me in contact with other professionals involved in the care of terminally ill residents from whom interviews could be sought. During this period a focus group/group interview will help to gain understanding about what nurses and carers find difficult about caring for a terminally ill resident and what they find encouraging about this experience.

A planning/facilitation phase – will then take place when issues that have been identified in the previous phase will be discussed, and clues to their solutions dynamically addressed with both nursing home staff and the primary care team as appropriate. Constant monitoring of both issues and solutions will allow modification and revisions to be made. A planned monthly reflective meeting with yourself will give two-way feedback and provide support for both of us during the process of change. You would have the option of keeping a reflective diary to help remind you of any issues you wanted to mention at the meeting. During this time I will still be involved in working alongside side and observing care to dying residents and their families. I am likely to be in the nursing home for 2-3 shifts a week during this period.

A final evaluation – will be carried out at the end of the study. This is likely to be in the form of interviews (group and/or single), and/or a questionnaire.

It is hoped that after being involved with the Bridges Initiative for one year, that the nursing home manager/matron and the nurses/carers will not only have built on their own knowledge of care for dying residents, but have established new contacts to help and support such care in the future.

Your decision to be part of the Bridges Initiative is entirely voluntary. If after reading this information sheet you decide you don't want to take part please just say so. Similarly, if you agree to take part you have the right to withdraw from the study at any time should you so wish.

I can be contacted at [Hospice] if there are any queries about the research. Independent advice about the research can be sought from [name of person/address]. The study has been approved by the local ethics committee.

Jo Hockley
[contact details] June 2000

APPENDIX 2a

The 'Bridges Initiative'

CONSENT FORM

(focus group/interview)

Thank you for agreeing to take part. This focus group/interview will look at issue related to caring for elderly residents who are dying in the nursing home

- I agree to participate in this focus group
- I have read this consent form and had the opportunity to ask questions
- I agree to the discussion being tape-recorded. I understand that anonymity will be assured and that it will not be possible to identify individuals from any written accounts that result from the discussion
- I understand that I am under no obligation to take part in this group and that I can withdraw at any point

NAME OF PARTICIPANT…………………………………………

SIGNATUR OF PARTICIPANT…………………………Date………………………

APPENDIX 2b

The ‘Bridges Initiative’

CONSENT FORM

(NH owners/nurse managers)

I ………………………….. have read the information sheet about the ‘Bridges Initiative’ and discussed it with the rest of the team at [name of nursing home]. As a team we are willing to take part. I know that we as a nursing home can withdraw from the project at any time.

NAME …………………………………… Signature ………………………………

ADDRESS ………………………………
…………………………………………..

Date …………………………..

APPENDIX 2c

The 'Bridges Initiative'

CONSENT FORM

(staff)

I ………………………….. have attended the presentation and/or read the information sheet about the 'Bridges Initiative' and am willing to take part as a member of the caring team at [name of nursing home]. I know that I can withdraw from the project at any time.

NAME …………………………………… Signature ……………………………….

ADDRESS ………………………………
……………………………………………..

Date ………………………..

APPENDIX 3

FOCUS GROUP DISCUSSION OUTLINE

START with 'ice breaker'

Preamble
My experience in palliative care is within the hospice movement.
BI looking at dying in NHs some of which involves cancer but majority non-malignant disease.
By palliative care I mean 'advanced progressive disease'.

LISTEN

Q1 What do ***you*** feel is central to the care of palliative care residents at [name of NH]?

Summarize issues…..then
Anything else?
What works in practice?

Q2 What might some of the DIFFICULTIES be?

Q2 I'm interested to hear more views on aspects of 'communication' around the time when a resident becomes frail and ill, and is dying. And indeed after they have died. *Talking with* residents, their families, other residents and indeed staff. How is that for you as nurses and care assistants?

Q3 The 'key person' role to help the residents with shopping needs etc. How much does that role apply to the palliative care situation and the residents/families needs when that person is dying?

Q4 Within palliative care 'endings' are seen to be relevant in order for people to move on. How is that for the family, other residents, even yourselves when a resident has been here over a reasonably long period of time.

Q5 What aspects of palliative care would you like to see being explored further in NH1/NH2a/NH2b?

APPENDIX 4a

Semi-structure interview outline (relative)

- I was wondering when you first realised that [name] beginning to deteriorate and how much that was your understanding and how much it was communicated to you by staff in [NH]?
  - What about your mother/father….did they talk with you about it?
  - Did they ever mention they thought they knew they were dying?

- Some people find it hard to visit because of living away or pressures of work etc. Was that an issue for you?

- Were there things about the care your mother/father received at [NH] that were particularly special and important to you?
  - Were there things that you felt you would have liked done? Prompts:
    - More opportunity to speak with doctors
    - Explanation/support/communication
    - Control of distress

- How did you feel the last few days of your mothers/fathers life were managed?
  - Peacefulness/distress
  - Their needs
  - Information

APPENDIX 4b

Semi-structure interview outline (professionals)

Over the last 10 years, deaths in nursing homes have risen considerably in [health board]. That's partly because of an increase in the number of nursing homes in the 1990s. How has that affected your work with residents in nursing homes?

Caring for older people in nursing homes isn't easy – one hears about 'good' and 'bad' nursing homes – what is your opinion makes a 'good' nursing home in their care of dying residents?

- Teamwork, open communication, families, symptoms: pain/agitation
- What about 'bad' nursing homes?
  - Staffing
  - Financial issues

How do you feel going to visit a dying resident in a nursing home? Is this any different to visiting a person in their own home or a residential home?

- In what way are deaths different in NHs?

What specific palliative care education/training have you had?

How do you feel the recent publicity about Harold Shipman's case might have affected the care of the older people generally?

- Has it had any affect on you personally?

APPENDIX 5

Documentary pro-forma from resident's plan of care

NURSING HOME: Room No:

Name: DOA:

DOB DOD:

Named Nurse: Carer:

Next of kin:

Address/Tel:

GP

Address/Tel:

Transferred from: Home Hospital Hospice

Reason for admission:

Problems/diagnoses on admission:

Drugs on admission/changes:

…continued /documentary pro-forma

Life history/family tree:

Mental and emotional state (sociability, behaviour, confusion)

Symptoms (pain, infections, falls etc.)

Care management (including: nursing dependency, hospital admission, GP involvement, use of equipment)

Record of final drug regime given:

APPENDIX 6

CONTACT SUMMARY & INITIAL ANALYSIS FORM:

(adapted from Miles & Huberman, 1994)

Nursing Home: Date coded:

Type of contact: CLG, interview, focus group Date:

Those present:

Page	SALIENT POINTS	THEMES

APPENDIX 7

Nursing Home 2 – 'Bridges Initiative'

- Interim Report NH2A following 4-month 'initial phase'

Introduction

NH2 is a medium-sized nursing home run by a 'non-profit making' organisation that comprises two nursing homes, a residential home and sheltered housing accommodation. The accommodation at NH2 is on two floors with a third floor used for storage/offices.

NH2 is well established as a nursing home being granted nursing home status in 1992 but had operated previous to this as a residential home for many years. Because of its size, the home gives more of a sense of an institution than the smaller nursing homes. However, the way care is given and the relaxed but efficient way the home is run considerably diminishes these feelings. It is highly respected as a 'well organised and efficiently run nursing home' (comments from GPs and families of residents interviewed). The gardens are well maintained and available for residents to wander around quite safely on their own.

Personnel from the organisation come into the home to do house repairs, and gardening. An 'activities co-ordinator' runs different groups for the residents as well as doing one-to-one work with residents who have varying degrees of cognitive impairment (including exercise classes, reminiscence groups, literature/current affairs groups etc). Residents who are able go once a week to a social club that is organised for the various facilities. The cooks and kitchen staff (a team in itself) work in a large purpose built kitchen and mix with the rest of the team in the staff coffee room at breaks but are managed by the Catering Manager.

A relatives group has recently been set up in order to support relatives of residents within the home giving them an opportunity to raise current issues. The nurse manager currently runs this but it is hoped that it will gain its own momentum.

Aspects of care

Organisation of nursing care

The nurse manager, two sisters, trained nurses and care assistants are all committed to providing excellent care to the 41 residents in NH2. An impressive feature of the care given is that it is 'patient-focused'. The care is modelled around resident autonomy and dignity with power being devolved down to care assistants taking on the status and responsibility of 'key workers'. Trained nurses have specific 'named nurse' responsibility in overseeing the care given.

There are a total of 15 trained nurses and 23 care assistants. There is regular agency staff covering night duty shifts but the use of agency staff during the day is kept to a minimum. At present the home is working with one daytime trained nurse post unfilled which clearly puts pressure on other staff during holidays/sickness. There is considerable evidence that the views of staff are regularly sought over various issues. Night nurse meetings, care assistant meetings and trained staff meetings are held regularly. An enormous amount of the nurse manager's time is given over to support these meetings.

The general attitude of welcoming and managing 'change' is inherent in the care culture of NH2. The Minutes of a recent meeting about 'change' were displayed on the notice board in the staff room. This is an *extremely* refreshing aspect and is due to the central value of the nurse manager's work ethos. Since 'action research' is about implementing change this will be an enormous benefit to the project. NH2 has a feeling of being 'alive' and not ossified into a past age of the routinisation of care. There is a strong sense that both residents and staff are people whose opinions are respected and this is clearly led by the nurse manager.

Change, however, is never easy. Individuals both within the focus groups and in the individual interviews readily discussed the scenario of a recent change endeavour concerning funeral directors using the front door of the home. The implemented change was subsequently rejected by the care staff. The maturity and honesty with which the change was discussed within a team context was admirable.

At the beginning of this first phase at NH2, there was considerable communication given between trained nurses and carers at the 'team hand-over report'. This was also an opportunity to report about deaths of residents that had occurred. I was impressed that nursing staff were very aware of staff who had been away on days off/holidays and how they would re-cap before the 'team hand-over' started about death/s that had occurred during their absence. Such a meeting also helped nurses and carers to act like a team. However, an incident that occurred more recently highlights that with formal 'team hand-overs' now disbanded and the communication happening in two separate meetings, communication may not be so streamlined and the immediate passing on of information regarding a death may get missed. This is not only a shock for the carer but puts both the carer and the relative in an awkward position when it is the relative who tells the carer the resident has died.

The main concern that was stressed many times both within the focus groups and while helping with the work, was the lack of time staff were able to give not only to the dying but quality time to other residents……"You know what you want to do but physically there is just not the time". Carers felt it was very important to be with the dying and have time to talk or just sit quietly with them. However, often the pressure of attending to the other residents in their charge meant that the dying residents were 'left to last' in order to be able to spend time with them. Even so they felt the care given was often rushed with interruptions from the other residents allocated to their care. Even having someone who was dying often meant that carers were still required to look after their full five residents. Carers would have preferred to have two people doing the caring with dying residents but this was often impossible because of what was felt to be a 'lack of staff'. Nonetheless, the care given by most of the carers/nurses I worked with was impressive with many of them showing particular attention to detail. There was considerable evidence from two of the trained nurses of a willingness to make time to speak with the families of residents who were seriously ill.

Some carers felt that the trained nurses sometimes 'took over' the care when a resident was dying. If it is an inexperienced carer then this may be appropriate but coming alongside a new carer can help mentor them through such a situation. However, if time is pressured then mentoring is often the first thing to go. Greater teamwork could compliment expertise on both sides. In fact with the expertise that some of the senior care assistants have there could be a case for trained staff monitoring them more like student nurses. Interestingly, the focus groups were mostly attended by care assistants and although a third focus group was planned for trained staff it was still difficult to persuade all the trained nurses to attend. There are clearly several reasons for this but at times there did feel to be a slight trained nurse/carer divide that might be inevitable in a larger nursing home.

Many carers found the physical aspects of caring for the dying rewarding but found dealing with families, and other residents questions particularly stressful. Many felt it was important to be with the dying because that would be how it would be at home if the resident was at home. They saw the nursing home as an extension of that sort of care which is admirable.

Pain and symptom control:
Chronic pain is a considerable problem in most nursing homes – evidence from recent surveys in the literature. This is partly because the elderly 'put up with it' believing that it is part of getting old, and partly because of the lack of formal assessment tools to assess pain in people who have dementia alongside the lack of formal education for nursing home staff. Carers felt that sometimes their reports of residents being in pain were not acted upon. They felt listened to but pain was often not attended to 'formally' with regular analgesics unless the nurse manager took specific responsibility for making it happen. One resident in particular has consistently complained of pain for several months. There have been several interruptions to this resident's care at NH2 including admission to hospital but it is only after a number of months that her pain is being addressed. The resident in question has the misfortune of having a GP who the team feel is not particularly interested in coming to the home to see patients. With more training the trained nurses within the team could take the responsibility and specifically address pain issues.

Pain perhaps was not consistently reported and managed but things like inflammation, sacral sores, constipation, urinary tract infections were well reported and treated. There was no evidence of any deep pressure sores despite some residents being totally bed bound. Any superficial sacral grazing was immediately addressed.

Most of the trained staff were very aware of the constipating effect of analgesics however there was sometimes a lack of knowledge re the dose of specific aperients necessary for residents on regular analgesics. There was a plea for the use of more liquid medication for frail elderly residents. It was felt though that this was not forthcoming often because of liquid medications were thought to be 'more expensive on the GP's budget'.

Education

There is considerable education that is given to staff working in NH2 especially for the trained nurses. All staff attend the obligatory 'Lifting and Handling' and 'Fire and Safety' and many also have the opportunity to attend other courses as and when they come up. Financial help for education was in no way limited and a very positive aspect of caring for staff in the home. One or two have been on specific grief and loss study days and a couple of the care assistants were sent on the Hospice 3-day course for care assistants.

Many of the care assistants during the focus groups, as well as documentation in their confidence questionnaires, wanted more knowledge on caring for residents who are dying. It was apparent that a lot of the practical palliative care knowledge appeared to be 'handed on' through informal caring. However, the carers' main concerns were as basic as not feeling confident doing 'last offices', knowing how to support families visiting a resident who was dying, and sitting with dying residents. Much of this is very practical and wouldn't necessarily be covered in the 3-day care assistant course at the Hospice.

GPs commented on the keenness of the nurses to learn and that the knowledge base was very good. This knowledge base could be enhanced especially amongst those who have had least experience as trained nurses in the home through reflecting on the practice of palliative care and thereby increasing both individual and team knowledge.

The night nurses/carers did not attend any of the focus groups. It will be difficult but some way of including them in teaching/education specific to care for the dying would be important.

Bringing death/dying more into 'the open' within nursing home care

Death and dying is not seen as a secretive thing in NH2 but many care assistants didn't know what they were allowed to say. If other residents asked about the condition of one of the other residents in the home who they knew was very ill, they found this awkward. Bringing death and dying more into the open within nursing home care is something that the nurse manager sees as an important aspect of the care at NH2. If staff had more confidence these awkward situations could be used as a positive opportunity to enquire how the resident enquiring was feeling and, if appropriate, an opportunity taken to talk more pro-actively about fears of death/dying. Again, there was evidence of some of the trained nurses having the skill to do this but others tended to 'opt out'.

Although we might not realise it, death/dying is not far from the thoughts of many residents in nursing homes as the following vignette details:

> While visiting the Summer Fayre at NH2, I was leaning over looking at a number of things for sale on a table including some CDs. One of the residents that was already at the table pointed to and commented on the CD that was on top of the pile…….it was a 'Funeral March'! She was not distressed by it at all but her very remark made me realise that we might not be addressing aspects of spirituality to do with death and dying as often as some residents might want. On another occasion a resident thanked a staff member for 'breaking the spell' of having a succession of women residents dying in a room with the admission of a male resident. Another opportunity for exploration.

Staff and in particular carers do find it difficult to know how to behave especially when the funeral directors come to collect someone who has died. Many comments were made indicating that often the truth about what was happening was hidden from those who were cognitively impaired because of a feeling that it was kinder. The researcher was impressed by an incident that came to light in one of the focus groups. One of the carers explained how just the other week she had been coming out of a resident's room with the resident when the funeral directors were removing a body from the home. As the coffin passed, the resident gently bowed their head until it had passed. This seemed to the carer and to others listening in the focus group an impressive way to cope with such a situation and quite a lost art.

Support when caring for the dying

Caring for the dying is one of the most stressful aspects of care nurses/carers have to cope with. Staff needs are uppermost in the nurse manager's mind and the very fact that various staff meetings are held is a clear indication of this. However, it was felt by the nurse manager in particular that often deaths would go by without the opportunity to support the team. One example of this had been when three of the residents had died on the same day earlier in the year. The nurse manager had wanted to sit down with the team but the busyness within the home appeared to work against this.

There was clear evidence of informal support….'anyone can go to anyone'. However, the concern of carers about coping with death was evident………'death isn't something you've faced before you come and work here'………..'I never thought I would be dealing with dying when coming to work in a nursing home'…………..'to think a death has happened in a building that you've been in is terrible'. One carer explained how she had handed in her notice after experiencing her first death when working in her first nursing home – she found it 'so shocking and was totally unprepared not realising that

that sort of thing happened in nursing homes'. There is considerable concern about the change in the frailty of residents being admitted to nursing homes and this will inevitably impact on staff caring in nursing homes.

To impact on the above there were a considerable number of staff (eight in total) that have had personal deaths to cope with, some of whom have not fully resolved the impact of the death on them. This makes working with the dying stressful and difficult for them. The outcome inevitably is that caring for the dying either puts an added strain on the carer/nurse personally or they will avoid getting involved in order to obviously protect themselves from the hurt.

Staff found professionals coming into the home to help advice on the care of the dying very helpful and welcomed the support. Families also felt that the regular visits of a GP during the dying phase, even though they did not expect any change in treatment, very supportive and a vital component in the total caring.

Equipment

There was a good range of equipment for the daily needs of residents' care in NH2. Differing types of hoists, wheelchairs, beds, bed-safety rails, airflow/spenco mattresses were well used. Specific equipment such as syringe drivers were used when a dying resident needed it. However, knowledge of its use and the necessary equipment such as syringes, occlusive dressings, butterflies were limited and often had to be sought as an emergency. More simple things like dressings were rather erratically stored in either the treatment room or the linen cupboard. However, I know plans are underway to move the treatment room because of the heat.

What pervades the general morning activity of the nursing home the most is the noise of 'buzzers'! Clearly after a while one gets used to them and cope with blocking them out of mind. However, even though one is able to block it out of one's mind it nonetheless adds a stress to the working day. During a night shift it was a wonderful relief to see carers/nurses carrying 'bleeps' in their uniforms in order to be alerted to a resident's need. It is clearly difficult for that to happen during the day. However, some solution could be worked out with the front door alarm! The front door alarms when it is opened and then again when it is closed behind someone. During the morning work there are not enough carers/nurses to attend to the front door buzzer each time someone exits the building. A few of the residents do know the number of the front door exit but I have never seen them abusing it! Also, the rear door near the kitchen is alarmed but since staff cannot hear the alarm in the kitchen it is often buzzing without their knowledge. On several occasions it was the back door alarming that went on for a good 15 minutes before I went to turn it off myself.

The wider inter-disciplinary team

Chiropodist, physiotherapists, community dentists, visiting chaplains, a number of different GPs from 5 surgeries are regular visitors to the home and make up the peripheral inter-disciplinary team.

GPs whose patients had died during this phase of the study were interviewed. They were very impressed with the care given to residents at NH2. There was some concern about the rapid change over of trained staff but this mostly came from GPs that only had a small number of patients at the home and therefore visited infrequently. One GP remarked he had had to get to know three different nurse managers in the last five years. However, it was felt to be inevitable because caring for the older person in nursing homes was 'very demanding and lacked a proper career structure for nurses without the same remuneration as those working within the NHS'. The GP was seen to be a very important member of the peripheral team for the care of residents. However, there was some feeling that they were on the periphery of care. One GP did a formal monthly round while most of the other GPs would be contacted as necessary. Clearly there are both advantages and disadvantages of having only one or two surgeries only involved in the care of residents at the nursing home. The advantages are that care is more streamlined and GPs have a greater opportunity to get to know the staff and residents on a regular basis and even do a proper 'ward round' seeing all the residents under their care once a month.

The care model of nursing homes differs remarkably from other models of healthcare and in fact 'puts the medical model on its head' as one GP put it. This puts a huge, but in my mind appropriate responsibility, onto the trained staff in the home. One GP specifically felt that doctors *should* be on the periphery and congratulated nurses in nursing homes from turning the medical model of care on its head. However, if this is really the case, and it could be more likely to become a more accepted model of care with the growing interest in a specialist gerontological nursing qualification, then trained nurses need to be more adept at being involved in end-of-life decision making. With some of the trained nurses (by no means all), decisions were very much left to the doctor despite the nurse knowing the resident better. Issues were likely to be more difficult when GPs were called to see a resident who they themselves had not met before. In this situation the nurse in charge was often less confident about challenging inappropriate decisions. It is important that all trained members feel confident to query a GPs suggestion on a palliative care issue if a decision is being made that isn't in the resident's best interest.

Difficulties working within an inter-disciplinary model:
There was considerable frustration amongst the trained staff about the lack of care from one particular surgery and the inability to get the professional medical help that they felt was often needed. Now it may be that this surgery is particularly pressured at present for whatever reason. However, when Lothian Health pays surgeries an extra payment to visit their patients in nursing homes then there is an expectation that that professional care is forthcoming. In such difficult situations there may be a case for the trained staff

to re-register the resident/s with another practice after necessary consultation. Otherwise there is a tendency that frustration with not getting the help will immobilise appropriate action.

One incident in particular stands out when staff at the nursing home were caught unaware. There was concern about a resident and when the surgery was phoned to see if a doctor would visit it was suggested that the resident go to the surgery to be seen because of the lack of doctor availability. In itself this would not seem to be a problem, however it not only took a carer away from NH2 but put a huge responsibility onto the carer. The resident had advanced dementia but, despite this was admitted straight to hospital from the surgery with the carer feeling helpless to intervene. If the GP had been able to visit the situation could have been discussed with the nurse in charge and a planned admission carried out with the needs of the resident fully recognised. As it was the resident spent 3 distressed days in a surgical ward without anything being done under the care of nurses inexperienced in the care of patients with dementia.

Communication during and after a person has died

During the dying period relatives found the care given to the resident exceptionally good on the physical side. However, there was little expectation on the part of some relatives for the need to an open dialogue about dying………… 'It was obvious – so you didn't have to say – we all knew'. Part of the caring for dying residents is in the care given to the family/relatives. The importance of being pro-active in this kind of caring and being able to speak about dying openly can help to prepare relatives for the inevitable and thereby reduce stress at the time of death. Such a skill was very much in evidence with the nurse manager and a couple of the other trained staff. However, such a skill is often only established with knowledge/support in doing it, alongside a willingness to learn.

The effort staff make to attend funerals often in their own time is really appreciated by relatives. It also shows not only the commitment that staff have for the residents they care for and their desire to be involved in the 'endings' of peoples lives but also the standard quality they work by.

With the changing role of nursing homes, the trained nurse is being asked to play a much more pro-active role in the decisions and care of frail and ill residents.

Jo Hockley, July, 2001

APPENDIX 8

EVALUATION QUESTIONNAIRE

Please circle: **Trained nurse** **Care assistant**

The following questionnaire is likely to take about 15 - 20 minutes to fill in. I would really appreciate it if you could take this time to complete the form so that we can evaluate the 'Bridges Initiative' so far – we have another 4 months still to go. Once the questionnaire has been completed, please place it in the large envelope on the 'Bridges Initiative' Board.

1. Please state how long (years + months) you have worked at [name of NH]:
.... other nursing homes:

2. In relation to the following aspects of the 'palliative care approach' to what extent has the project influenced your knowledge in respect to end-of-life care on the following on the following aspects:

	'Yes'	**'Some'**	**'No'**	**'Don't know'**
a. Improved quality of care to dying residents including good symptom control?	☐	☐	☐	☐
b. Improved support of relatives of dying residents?	☐	☐	☐	☐
c. Better support of staff during/after a death?	☐	☐	☐	☐
d. Improved communication around issues of dying?	☐	☐	☐	☐
e. Improved multi-disciplinary involvement in the care of dying residents/families?	☐	☐	☐	☐

.../Continued over the page

3. Over the last 8 months a number of different ways of improving knowledge on caring for dying residents at [name of NH] have been introduced. In the questions below, please circle the appropriate figure on the 0 – 10 rating to indicate the unhelpfulness/helpfulness of the action. Then please take time to write what was particularly helpful/unhelpful. *If you did not take part in something please circle '**N/A**' by the appropriate question.*

EXAMPLE: *How helpful did you find the **mouthcare video?***

Unhelpful 0 2 4 6 8 10 *Very helpful*

a. How helpful did you find the **'collaborative learning groups'** following a death?

N/A

Unhelpful 0 2 4 6 8 10 *Very helpful*

Please write down what made the 'reflective de-briefing sessions' particularly helpful or unhelpful:

b. If you used a **reflective diary** how helpful did you find it as an aid to learning?

N/A

Unhelpful 0 2 4 6 8 10 *Very helpful*

Please write down what you found particularly helpful or unhelpful about keeping a reflective diary:

c. How helpful did you find the workshop on **'syringe drivers'**?

N/A

Unhelpful 0 2 4 6 8 10 *Very helpful*

In what way was this workshop particularly helpful or unhelpful:

d. How helpful did you find the tutorial on **'last offices'**?

N/A

Unhelpful 0 2 4 6 8 10 *Very helpful*

Please write down what you found particularly helpful or unhelpful about this tutorial:

e. How helpful did you find the tutorials on **'pain assessment and pain management'**?

N/A

Unhelpful 0 2 4 6 8 10 *Very helpful*

Please write down what you found particularly helpful or unhelpful about this tutorial:

f. How helpful did you find the tutorial on **'grief and loss'**?

N/A

Not helpful	0	2	4	6	8	10	*Very helpful*

Please write down what you found particularly helpful or unhelpful about this tutorial:

g. How helpful did you find the **'working alongside'** a clinical nurse specialist (Jo) when residents were actually dying? For instance, in direct patient care or advising on symptom control issues.

N/A

Not helpful	0	2	4	6	8	10	*Very helpful*

In what way did you find this particularly helpful or unhelpful:

h. For those who attended study days at the Hospice, how useful was this?

N/A

Not helpful	0	2	4	6	8	10	*Very helpful*

What 3 things did you find particularly helpful or unhelpful

i. For those who took part in the 'exchange visit' to the Hospice how useful was it?

N/A

Not helpful 0 2 4 6 8 10 *Very helpful*

What 3 things did you find particularly helpful or unhelpful

4. In what ways has being involved in the Bridges Initiative helped you?

5. In what ways has being involved in the Bridges Initiative been difficult for you?

6. Has the project made a difference to the way you view caring for dying residents? If so, in what way particularly?

7. What further things would you like see done ?

Many, many thanks for your time – when completed please put in large envelope on the 'Bridges Initiative Board'.

APPENDIX 9

Date....... **Meeting number ....** **Stage in process ....**

Present: **Apologies:**

Discussion topic	**Action/Decision agreed**	**Action**
1.		
2.		
3.		

Reference clinical evidence used:

i)..
ii)...
iii)..

Items for next meeting:

Items for future considerations:

Next meeting:

Date ...... **Time.........** **Location ....**

49789

INTEGRATED CARE PATHWAY FOR THE DYING PATIENT PROJECT

BASE REVIEW

This is a scannable form - please complete carefully. Do not staple.
Please refer to guidance notes for completing document

Centre Name

CentreType

☐ Hospital ☐ Hospice ☐ Community ☐ Nursing Home

Patient Identifier

Pat Age

Gender (Please circle)

M F

Admit Date . .

Death Date . .

Primary Diagnosis - please refer to data dictionary (please tick only one)

Cancers:

☐ Bone (sarcoma)
☐ Breast
☐ Eye
☐ Meninges
☐ Brain
☐ Anus
☐ Colon
☐ Oesophagus
☐ Rectum
☐ Small intestine
☐ Stomach
☐ Adrenal
☐ Carcinoid
☐ Neuroendocrine
☐ Thyroid
☐ ENT
☐ Female genital organs
☐ Leukaemia
☐ Lymphoma
☐ MDS
☐ Myeloma
☐ Gall bladder

☐ Liver
☐ Pancreas
☐ Penis
☐ Prostate
☐ Testis
☐ Mesothelioma
☐ Other connective/soft tissue disorders
☐ Bronchus
☐ Non small cell lung
☐ Small cell lung
☐ Trachea
☐ Malignant melanoma
☐ Non melanoma
☐ Bladder
☐ Kidney
☐ Ureter
☐ Cancer of primary multiple sites
☐ Unknown primary
☐ Other cancer

Non cancers

☐ Acute abdomen
☐ Arthritis
☐ MI, CCF
☐ Stroke
☐ Alzheimers
☐ Epilepsy
☐ Motor neurone disease
☐ MS
☐ Parkinsons disease
☐ CNS: other
☐ Hepatobiliary
☐ HIV/AIDS
☐ Renal
☐ Respiratory
☐ Vascular
☐ Other non cancer

For "Patient Identifier" please enter a number which uniquely identifies your patient. Please enter it on each page in proforma

49789

Patient Identifier

COMFORT MEASURES

1.1 Pats current medication assessed and non essentials discontinued ☐ Yes ☐ No

1.2 If other medication not discontinued was a documented reason given ☐ Yes ☐ No

2 Was as required (PRN) prescribed subcutaneously: 2.1 Analgesic ☐ Yes ☐ No 2.2 Antiemetic ☐ Yes ☐ N

2.3 Anticholinergic ☐ Yes ☐ No 2.4 Sedative ☐ Yes ☐ N

2.5 If yes were drugs prescribed the ones recommended in your local formulary guidelines ☐ Yes ☐ N

3 Were the following interventions discontinued 3.1 Blood Tests ☐ Yes ☐ No ☐ Not applicable

3.2 Antibiotics ☐ Yes ☐ No ☐ Not applicable

3.3 Intravenous fluids ☐ Yes ☐ No ☐ Not applicable

3.4 Were do not resuscitate instructions documented ☐ Yes ☐ No ☐ Not applicable

3.5 Were instructions re do not transfer to hospital documented ☐ Yes ☐ No ☐ Not applicable

3a Were inappropriate nursing interventions discontinued:

3a.1 Routine Turning Regime ☐ Yes ☐ No ☐ Not applicable

3a.2 Taking vital signs ☐ Yes ☐ No ☐ Not applicable

3b Was a syringe driver set up within 4 hours of prescription ☐ Yes ☐ No ☐ Not applicable

PSYCHOLOGICAL/ INSIGHT ISSUES

4 Ability to communicate in English Assessed ☐ Yes ☐ No ☐ Not applicable

5.1 Patient aware of diagnosis? ☐ Yes ☐ No

5.2 If no is there a documented reason ☐ Yes ☐ No ☐ Not applicable

5.3 Patient aware s/he is dying ☐ Yes ☐ No

5.4 Next of kin aware patient is dying ☐ Yes ☐ No

RELIGIOUS NEEDS

6.1 Patients religious needs assessed ☐ Yes ☐ No ☐ Not applicable

6.2 Patients religious needs met ☐ Yes ☐ No ☐ Not applicable

COMMUNICATION WITH FAMILY - OTHERS - PRIMARY HEALTH CARE TEAM

7 Identified how family/others were to be contacted/ informed of patients impending death? ☐ Yes ☐ No ☐ Not applicable

8 Family/others given written information re facilities ☐ Yes ☐ No ☐ Not applicable

9 Patients GP/locum service aware that patient in dying phase ☐ Yes ☐ No

10 Patients plan of care discussed with family/others ☐ Yes ☐ No ☐ Not applicable

49789

Patient Identifier

SECTION 2: ONGOING ASSESSMENTS

S2.1 Assessment of pain 4 hourly/each visit ☐ Yes ☐ No

S2.2 Was the patient in pain ☐ Yes ☐ No

S2.3 Was prn analgesia given ☐ Yes ☐ No

S2.4 Assessment of nausea & vomiting 4 hourly/each visit ☐ Yes ☐ No

S2.5 Was nausea & vomiting a problem ☐ Yes ☐ No

S2.6 Was prn antiemetic given ☐ Yes ☐ No

S2.7 Assessment of Agitation 4 hourly/each visit ☐ Yes ☐ No

S2.8 Was agitation a problem ☐ Yes ☐ No

S2.9 Was prn sedation given ☐ Yes ☐ No

S2.10 Assessment of excessive respiratory secretions 4 hourly/ each visit ☐ Yes ☐ No

S2.11 Was excessive respiratory secretions a problem ☐ Yes ☐ No

S2.12 Was prn anticholinergic given ☐ Yes ☐ No

S2.13 Assessment of mouth care 4 hourly/each visit ☐ Yes ☐ No

S2.14 Assessment of Micturition problems 4 hourly/each visit ☐ Yes ☐ No

S2.15 If pressure relieving aids required were these provided ☐ Yes ☐ No

S2.16 Assessment of Bowel Care 12 hourly/each visit ☐ Yes ☐ No

CARE AFTER DEATH

S3.1 GP/Locum Service contacted re patients death ☐ Yes ☐ No

S3.2 Post mortem discussed ☐ Yes ☐ No ☐ Not applicable

S3.3 Special needs identified /religions / infection needs ☐ Yes ☐ No

S3.4 Family/others informed of tasks following death ☐ Yes ☐ No

S3.5 Appropriate documentation given to family/others ☐ Yes ☐ No

APPENDIX 11

INTEGRATED CARE PATHWAY FOR THE LAST DAYS OF LIFE

Pilot of Version 2

(adapted from Liverpool ICP)

AIMS:

- ***to continue to provide person-centred/holistic care & support to the resident who is dying – bringing physical, mental, emotional & spiritual comfort***
- ***to enable the provision of support and care to the relatives/friends of the resident who is dying***
- ***to provide instruction to staff caring so that staff feel more competent to enhance a kind, thoughtful, and professional attitude to death***
- ***to provide a more 'open' communication around issues to do with death and dying***

A Care Pathway is intended as a guide to treatment and an aid to documenting a person's care progress. Clinicians are free to exercise their own professional judgements as appropriate. However any alteration to the practice identified within this ICP should be noted as a 'variance' on the sheet towards the back of the pathway.

For further information please contact:

Jo Hockley

INTEGRATED CARE PATHWAY FOR A DYING PERSON

This integrated pathway provides a structured approach to providing care for a resident in their last days or hours of life. The pathway integrates the essential assessments with guidelines for potential problems and a multidisciplinary communication process. Although the pathway provides structure to the process of care, it should not replace clinical decision-making and judgement – particularly in complex cases. The pathway is split into 5 sections as follows:

Section 1: *Resident/family initial assessment* (white)

a) comfort measures
b) psychological insight
c) spiritual support
d) communication

Section 2: Resident/family ongoing problems/focus

4hrly assessments of: (Pale yellow)	*12hrly assessments on:* (Dark yellow)
a) pain/symptom control	a) bowel care
b) treatment/procedures	b) psychological insight/support
c) mobility/pressure area care	c) spiritual care
d) medication	d) care of family/others

Section 3: *Interdisciplinary communication*

Good communication is essential to good palliative care. The ICP and multidisciplinary notes sheet should be used by all staff.

Section 4: Variance reporting

Variance reporting is central to the philosophy of the integrated pathway. If a 'goal' is not achieved (variance) then a variance needs to be recorded in this variance section. Persistent variances (such as distress) should prompt the staff to refer to the guidelines (detailed in the next section).

Section 5: *Guidelines*

Guidelines give clear instructions (based on evidence & clinical experience of specialist) on how to address specific problems. The guidelines cover:

Symptom management including pain; use of fentanyl patches, syringe drivers etc
Obtaining palliative care medications out of hours;
The Final Act of Care – 'last offices'
Bereavement booklet/leaflet
How to contact specialist palliative care services

Instructions for use:-

1. The ICP is intended as a single record that replaces all other notes/care plans and is used by all staff.
2. All goals are in bold type. Prompts to help staff assess whether goals have been met are in normal type.
3. If a goal is not achieved (ie a variance occurs) then record this in the variance section (page 12).

Resident's Name: ………………………….. **DOB: …../……/…**

Date of Admission: ……/ ……/ ……. **Diagnosis: ……………**

Nursing Home: …………………

The decision to start a resident on the pathway should be made by the care team (GP + care staff). Some residents improve unexpectedly and it then may be appropriate to take them off the pathway. The following statements are taken from the BMA web-site. Answering 'yes' to three or more indicates appropriateness for ICP for the last days of life to be commenced.

The resident is:

Deteriorating without reversible causes	Yes	No
Semi-comatosed	Yes	No
Essentially bed bound	Yes	No
Taking little food/fluids and having difficulty with oral medication	Yes	No
Resident/family not wishing further investigations/interventions	Yes	No

GENERAL PRACTITIONER: **DATE entered on ICP:**

NAMED NURSE:

ALL PERSONNEL COMPLETING THE CARE PATHWAY PLEASE SIGN BELOW

Name (print)	Designation	Initials	Full Signature	Date
1				
2				
3				
4				
5				
6				
7				

NAME…………………… ROOM NUMBER……… DATE…..

SECTION 1

RESIDENT's INITIAL ASSESSMENT

PHYSICAL CONDITION

(If 'YES' to any of the problems in this small section, refer to the guidelines at back of ICP for advice on management)

Unable to swallow	**Yes ☐ No ☐**	Aware	**Yes ☐ No ☐**
Nausea/vomiting	**Yes ☐ No ☐**	Conscious	**Yes ☐ No ☐**
Constipated	**Yes ☐ No ☐**	UTI problems	**Yes ☐ No ☐**
Confused	**Yes ☐ No ☐**	Catheterised	**Yes ☐ No ☐**
Agitated	**Yes ☐ No ☐**	Pain	**Yes ☐ No ☐**
Distressed	**Yes ☐ No ☐**	Resp. tract secretions	**Yes ☐ No ☐**
Restless	**Yes ☐ No ☐**	Breathless	**Yes ☐ No ☐**

COMFORT MEASUSRES

NB: If you answer 'NO' to any '<u>goal</u>' please chart as variance (p.12)

Goal 1: Current medication assessed and non essentials discontinued:
Yes ☐ No ☐

Appropriate oral drugs converted to subcutaneous route and syringe driver commenced if appropriate. Transdermal medication continued or started as appropriate. Inappropriate medication discontinued

Goal 2: PRN s/c medication written up from list below as per Protocol:
(see blue sheets at back of ICP for guidance)
Yes (all drugs) ☐ Yes (not complete) ☐ No ☐

Pain	*Analgesia*
Nausea & Vomiting	*Anti – emetic*
Agitation/confusion	*Neuroleptic*
Respiratory Tract Secretions	*Anticholinergic*
Anxiety/fear	*Anxiolytic*

Goal 3: Discontinue inappropriate interventions:

Blood sugars	**Yes ☐ No ☐ N/A ☐**
Antibiotics	**Yes ☐ No ☐ N/A ☐**
Naso-gastric tube feeding/PEG tube/s.c.fluids	**Yes ☐ No ☐ N/A ☐**

Not for cardiopulmonary resuscitation (*please record below*)

Goal 3a: Decision to discontinue inappropriate nursing interventions taken:
Yes ☐ No ☐

Taking vital signs i.e. B/P, TPR

Goal 3b: Syringe driver set up within 4 hours of Doctors order:
Yes ☐ No ☐ N/A ☐

TIME that s/c prescription written/ordered by GP:

Goal 3c: Resident has 'comfort' equipment i.e. suitable mattress/ fan
Yes ☐ No ☐

If you have charted "No" against any goal so far, please complete <u>variance sheet</u> before signing below:

Nurse signature ……………………………… Date ……………….. Time ………..
GP signature………………………………… Date ………………. Time ………..

NAME:………………… …ROOM NUMBER ……… DATE: ……/ …../ …..

SECTION 1	Resident assessment (continued)
PSYCHO-LOGICAL/ INSIGHT	**Goal 4: Ability to communicate in English assessed as adequate:** **Yes** ☐ **No** ☐ (i.e.ethnic groups – consider translation service) **Goal 5: To encourage 'open' communication about resident's condition:** **Unconscious Yes No** **Is there recognition of dying** **a)** Resident ☐ ☐ ☐ **b)** Family ☐ ☐ **c)** Other (please specify): ☐ ☐ **Goal 5b: Any 'unfinished business' with resident/family has been attended to: Yes** ☐ **No** ☐
RELIGIOUS/ SPIRITUAL SUPPORT	**Goal 6: Religious/spiritual needs assessed with resident/family:** **Yes** ☐ **No** ☐ Formal religion: …………………………………………… Minister of religion (name) …………….. Telephone No: ……………….. Particular needs now, at time of & after death identified:- (please state) ………………………………………………………………………
COMMUNIC-ATION WITH FAMILY/ OTHER	**Goal 7: Family/other to be informed of resident's impending death:** **Yes** ☐ **No** ☐ At any time ☐ Not at night-time ☐ Staying overnight somewhere: ☐ (please specify) 1st Contact (Name + relationship to resident) ………………………… Tel no: …………………………………. Mobile …………………… 2nd contact …………………………………………………… Tel no: …………………………… Mobile ………………………………… **Goal 8: Family/other know they can telephone/visit at any time:** **Yes** ☐ **No** ☐ Accommodation arranged as appropriate. If staying: food/refreshment provided; washrooms & toilet facilities shown; comfortable chair/bedding provided. Any other relevant information given.
COMMUNIC-ATION WITHIN PCT	**Goal 9: GP practice has informed 'out of hours' service that resident is dying: Yes** ☐ **No** ☐ **'Hand-over sheet' faxed to local 'out of hours co-op': Yes** ☐ **No** ☐
SUMMARY	**Goal 10: Plan of care explained: Yes** ☐ **No** ☐ **Discussed with:** a) Resident ☐ b) Family ☐ c) Representative:☐ (please specify) **Goal 11: Family/other express understanding of plan of care:** **Yes** ☐ **No** ☐
If you have charted "No" against any goal so far, please complete <u>variance sheet</u> before signing below: **Nurse signature…………..Date……………………Time………………………** **GP signature……………..Date……………………Time………………………**	

NAME:.................................ROOM NUMBER .... DATE: ....../...../.....

SECTION 2: RESIDENT PROBLEMS/ISSUES – 4 HRLY

Example of assessments (enter in columns) **A = ACHIEVED V = VARIANCE**** **(SEE PG.12 for recording of variance)**	**02.00** **A**	**06.00** **A**	**10.00** **V**	**14.00** **V**	**18.00** **A**	**22.00** **A**
ASSESSMENT OF PAIN/COMFORT MEASURES						

Goa : Resident is PAIN FREE ▪ If awake, ask resident if they have pain ▪ If unconscious, is resident 'pain free' on movement?						
Goal: Resident is PEACEFUL: i.e. not agitated nor restless nor fearful ▪ Is the resident showing signs of delirium i.e. plucking at bedclothes? ▪ Is the resident twitching? If so make sure they are not having too much morphine ▪ Is the resident mildly restless? If so, exclude full bladder +/- constipation ▪ Does the resident appear fearful and therefore not wanting to slepp?						
Goal: Resident's BREATHING is calm and not noisy: ▪ Does breathing sound wet/bubbly? ▪ Is the respiration rate rapid?						
Goal: Resident is NOT NAUSEATED OR VOMITING:						

TREATMENT/PROCEDURES						
Goal: Mouth is moist & clean – fluids as appropriate ▪ See mouth care policy ▪ Mouth care given at least 2hrly						
Goal: Resident has passed urine &/or is comfortable ▪ Urinary catheterr if in retention ▪ Urine passed within last 4hrs (please indicate with *)						
Goal: Resident is comfortable & skin is clean/dry ▪ Full wash given (please indicate with*) or hands/face as nec. Pressure area care attended – state if skin not intact						
Goal: Resident's safety is ensured ▪ Use cot sides as appropriate						
CARERS/NURSES INITIALS:						

NAME:………………………………ROOM NUMBER ……… DATE: ……/ …../ …..

SECTION 2 (Continued) RESIDENT PROBLEMS/ISSUES – 12 HRLY
Trained nurse who is responsible for resident on each shift to complete as appropriate

PLEASE ENTER IN COLUMNS - A = ACHIEVED V = VARIANCE**
(SEE PG.12 for recording of variance)

MEDICATION	**Goal: All medication is given safely & accurately:** ▪ If syringe driver in progress – charted & CHECKED on appropriate chart every six hours ▪ If no medication is require please record as N/A	**02.00**	**06.00**	**10.00**	**14.00**	**18.00**	**22.00**
				06.00 (night shift)		**14.00-18.00 (day shift)**	
BOWEL CARE	**Goal: Resident is not agitated or distressed due to constipation or diarrhoea/overflow**						
PSYCHO-LOGICAL INSIGHT AND / OR SUPPORT	**Goal: Resident becomes aware of situation as appropriate:** ▪ Resident is informed of procedures. Touch/verbal communication continues **Goal: Family/representative expresses understanding of plan of care, prepared for resident's death & feels supported:** ▪ Check understanding ▪ Recognises that resident is dying ▪ Informed of measures taken to maintain comfort ▪ Explain possibility of 'rattly' chest, cold hands/feet, mottling of skin, irregular breathing.						
RELIGIOUS / SPIRITUAL SUPPORT	**Goal: Appropriate religious/spiritual support has been given:** Detail further visit/s as appropriate						
CARE OF FAMILY / OTHERS	**Goal: The needs of those attending the resident have been met** Information re refreshments/offered						
	NURSES INITIAL:						

NAME:.....................................ROOM NUMBER .... DATE: ....../ ...../ .....

INTER-DISCIPLINARY NOTES

DATE and TIME	Please enter further important information – especially regarding important conversations with resident, relatives, and /or representatives.	Signature

ICP – VERIFICATION OF DEATH + ADMINISTRATIVE PROCEDURE

NAME:…………………. DOB: ………………… DATE: ……………

Date of death: ………………… Time of Death: ………………

Persons Present: ………………………… Time death certified by GP: ……..

CARE AFTER DEATH

Goal 12a: GP practice contacted re death **Date: __/__/__** **Yes ☐ No ☐**
12b: Family/friend informed if not present **Date: __/__/__** **Yes ☐ No ☐**
12c: Other residents informed **Date: __/__/__** **Yes ☐ No ☐**
12d: Other services informed (i.e. social worker) **Date: __/__/__** **Yes ☐ No ☐**
12e: Inform Head Office, as appropriate **Yes ☐ No ☐**

Goal 13a: Procedures for 'final act of care' according to Nursing Home **Yes ☐ No ☐**
13b: Removal of body from nursing home carried out according to 'policy' **Yes ☐ No ☐**

Goal 14: Alternative procedure following death discussed or carried out:
N/A ☐ Yes ☐ No ☐
(If 'yes' please indicate)
Resident had infectious disease ☐ Procurator fiscal notified ☐
Post mortem discussed ☐

Goal 15: Family/other given information on what they need to do **Yes ☐ No ☐**

- Collect death certificate from NH/GP surgery/registrar
- To contact registrars office to arrange a time to register death
- To contact funeral directors to arrange funeral [Name of funeral director: ……………]
- If resident is to be cremated, a cremation form is signed by 2 doctors and sent to undertaker

Goal 16: NH policy followed for resident's valuables & belongings **Yes ☐ No ☐**

- Belongings listed and resident's room tidied + room to be locked.
- Valuables listed and put in safe. Returned to family and a signed receipt given

Goal 17: Necessary documentation + advice is given as appropriate **Yes ☐ No ☐**

- Pension book returned to DSS or given to family
- Notification of death form to be completed and <u>sent</u> to care commission
- Death entered into Residents Register

Goal 18: Bereavement leaflet/book given to relative/close friend **Yes ☐ No ☐**

- Explain re 'how to register death' + likely reaction to grief as in booklet

Goal 19: This form P/C or NH form 'after a death' completed/faxed to management **Yes ☐ No ☐**

Goal 20: ICP returned to resident's notes – now deceased. **Yes ☐ No ☐**

- Case notes kept for a minimum of 3 years from date of death

IF YOU HAVE CHARTED "NO" AGAINST ANY GOAL SO FAR, PLEASE COMPLETE VARIANCE SHEET (page 12) <u>BEFORE</u> SIGNING BELOW

Nurse Signature ………………………………………….. Date …………………

INTEGRATED CARE PATHWAY FOR THE LAST DAYS OF LIFE

VARIANCE FORM

Name: ……………   DOB: ………………..

Date & Time	**WHAT VARIANCE OCCURRED**	**WHY DID VARIANCE OCCUR?**	**ACTION TAKEN**	**Initials**
E.g.	Residents is not peaceful	Resident told me he is not in pain – feels frightened	Spoke to GP – Valium 5mg supps. To be given stat and can be repeated every 8 hrs if necessary	

GUIDELINES ARE AN INTEGRAL PART OF AN INTEGRATED CARE PATHWAY BUT ARE NOT INCLUDED IN THIS APPENDIX:

The guidelines cover:

Symptom management including pain; use of fentanyl patches, syringe drivers etc
Obtaining palliative care medications out of hours;
The Final Act of Care – 'last offices'
Bereavement booklet/leaflet
How to contact specialist palliative care services

APPENDIX 12

SCENARIO – 'ICP' TEACHING –

Molly Stevens is a 97-year old lady who has been at Shadowland Nursing Home for 18 months. She has a 95-year old husband who manages to look after himself in a ground floor, sheltered housing flat in Stockbridge. He used to visit everyday but now visits 2-3 times a week because of being frail. They have a son who is married and lives in Dunbar. Their other child is a daughter who works as a GP in Newcastle-upon-Tyne. She is not married.

Over the last 7 weeks however, Molly has deteriorated further – she has had a couple of chest infections which have been treated with antibiotics. She does not appear to be so hungry – can easily be tempted with puddings etc. but noticeably eating less. Over the past two weeks Molly has hardly eaten anything. She has become more gaunt. She sometimes will take fluids but this has become increasingly difficult. A fluid chart has been started. The daughter is visiting every other week-end and has specifically asked the carer if she can speak with the GP. She feels her mother's condition is deteriorating.

Monday, 21st June (afternoon) – After the week-end the nurse speaks to Molly's GP surgery requesting a visit because of Molly's deterioration. Later that afternoon Molly is being helped on to the commode in her room by Gail (senior care assistant) who knows her very well. Molly repeats, 'It's enough....enough...enough!' The care assistant hears what Molly is saying and replies, 'Enough of what, Molly?' Molly just repeats 'enough...enough'. Molly sits on the commode but after ten minutes hasn't managed to use it and is helped back to bed. The carer intuitively wonders whether Molly is talking about 'enough of living like this' and speaks with the staff nurse who records the event in Molly's care plan

Tuesday, 22nd June (morning) – GP visits as promised. He chats to the staff nurse and then they both go and see Molly. Overnight she has become more restless and groans. The GP listens to her chest and feels her pulse. She is hot to touch. He tries to speak with Molly but gets no real response other than Molly just staring at him with the occasional moan. She looks very cachectic and dry. The GP and nurse leave the room and discuss the situation. 'I am wondering whether we shouldn't try an antibiotic? She's definitely got signs of a chest infection. What do you think?' he asks the staff nurse. 'Well, I am not sure whether that is appropriate. Molly is 97 years old. Just yesterday she was saying to the care assistant...."enough....enough". I am not sure what that was about but I wondered whether she was asking us to let her die. Would you like to speak with the daughter in Newcastle? Do use the phone in the office! Also, I am thinking she may be in pain – at times she is not able to take all her tablets?'

The GP agrees to discuss the situation with the daughter and phones the daughter from the nursing home.

'I think you are right, staff! Having spoken with the daughter – perhaps we should concentrate on making sure Molly is comfortable and forget the heroics.' The staff nurse replies, 'You mean you think she is dying?' Both the GP and the staff nurse agree together she is dying and the nurse reminds the GP that the ICP (Integrated Care Pathway) for the last days of life needs to be started. Then they turn to the 'initial assessment' pages of the ICP. They discuss Molly's restlessness and inability to swallow all her medication. They decide to discontinue her oral drugs and start a syringe driver with Diamorphine 5mg + Methotrimeprazine 12.5mg to run over 24hrs. Molly has always had Bisacodyl supps prn if she became constipated so they decide to keep those on the prescription. The GP thanks the nurse for her help and leaves the nursing home at 2pm in time for his afternoon surgery. The staff nurse makes sure the prescription gets phoned through straightaway so that the drugs can be started as soon as possible.

Just as Gail is going off duty she pops her head into the staff room to tell the report that Molly has been transferred to a spenco mattress and bedsides put on the bed but not pulled up. As the staff nurse continues to report back about Molly she suggests that the nurse in charge of Molly's care on the 'late shift' phones Molly's minister who has always visited regularly and tell him it is thought that Molly is dying. "If the son doesn't visit that evening then he too needs to be spoken to about the change in Molly's condition." **[complete initial assessment].**

June 22nd (afternoon) – The newly qualified staff nurse in charge of Molly's care has never come across an ICP before. She reads the notes and Sue (care assistant) helps her to understand what has to be done. They turn to Section 2, and go together to Molly's room to complete the sheet for 14.00hrs. When they arrive up in Molly's room, Molly has her legs over the side of the bed and is restless. The new staff nurse is aware that sometimes restlessness in the last days of life can be because of being uncomfortable but also because of constipation or a full bladder. She asks Sue whether Molly has had her bowels opened. Sue confirms she had a good bowel motion two days ago but explains that apparently Molly's pads have been 'dry' this morning + during the night. The staff nurse and Sue help Molly back into the middle of the bed. As she does this, the new staff nurse takes the opportunity to see if Molly's bladder is full. She puts her fingers over where the bladder is positioned and taps carefully with the other hand. There is a definite sound of fluid present in the bladder. While the staff nurse goes to get a catheterisation pack, Sue offers Molly some water and then cleans the mouth from the mouth tray and waits for the staff nurse to return. Directly the bladder is relieved of its 1 litre of urine, Molly settles and appears very comfortable. The care assistant goes in again regularly during the shift making sure that Molly was comfortable. At 18.00hrs she did all the next 4hrly checks. All was well **[complete 4hrly assessments].**

Molly has a very comfortable night – with nothing new to report. She is turned regularly, the catheter is draining well and her mouth is not too dry and quite clean. Molly has occasionally sucks on a wetted piece of gauze/sponge stick. **[complete 4hrly assessments].**

Wednesday, June 23rd (morning) – Gail is caring for Molly to-day. At 08.15hrs, before seeing to the breakfasts, she goes in to see how Molly is. She is peaceful but rousable. Gail decides to help Molly with a little drink if she is able, clean her mouth and change her position, but wants to come back to do her full care after she has helped her two other residents to have a bath. As she turns Molly with the help of another carer she notices that the catheter is draining urine properly At 09.30hrs the minister of Molly's church arrives to see Molly. Gail feels bad that she hasn't had a wash but at least her mouth is clean and she looks comfortable. Gail and another carer return at 11.00hrs to give her a nice wash. They offer some fluids but Molly pushes away the beaker **[complete relevant pages].**

June 23rd (afternoon) – All is well until the care assistant reports to the afternoon nurse at 18.00hrs that Molly's breathing has become noisey and wet. She records it as a 'variance' on the chart and then gets the nurse to write up the variance on pg 12. The nurse explains to the care assistant that there is a very good drug that helps to dry up chesty secretions in the last days of life and looks at the prescription chart to see if it has been anticipated by the GP who started the ICP a couple of days ago. Yes! She reads at the side of the prescription – to be given for 'rattly chest'. She decides therefore to give one dose to see if it helps Molly's chestiness since she thought it might be quite distressing for the family. Just as they are going off duty the care assistant checks Molly. All is well. **[complete relevant pages].**

Molly has a very comfortable early part of the night but at 06.00hrs the night care assistant notices that Molly's respiration are very shallow and goes and gets the staff nurse. The staff nurse agrees that Molly's condition has deteriorated and that they need to call the son as he wanted to be informed at 'any time' if his mother's condition deteriorated. She is also very aware that Molly's husband has not visited since Monday since that was a concern of the day staff. She would discuss this with the son. Meanwhile she suggests that the care assistant sits with Molly.

At 07.00hrs Molly's husband and son arrive. The staff nurse explains that Molly is now very poorly indeed. She takes them up to Molly's room and the care assistant pulls up some chairs for them to sit on. The staff nurse stays to chat while the care assistant goes to get the son and husband a cup of tea. Just as she leaves she hears the son tell the staff nurse that he has rung the daughter in Newcastle and she getting the train straightaway and he will go and pick her up from the station. The care assistant realises that the husband is likely to be alone with Molly if the son is going to the station so makes a mental note to keep popping in to Molly's room.

The staff nurse is due to go home at 08.00hrs but pops in to see Molly before she goes. As she enters the room she sees that Molly's respirations are now very laboured. The husband is sitting there next to Molly but doesn't seem to be registering how close to death Molly now is. The staff nurse could easily just have left the room and pretended she didn't notice; but, she didn't. She stays despite it being time for her to go off duty. She draws up a chair beside the husband and gently gets into conversation. She then starts to speak of how she thinks Molly is very close to 'leaving us'. Molly's husband seems surprised. The staff nurse leans across and feels Molly's pulse – it is thin and thready. What with this and the very irregular respirations with long gaps between each breath, Molly was imminently going to die. She was so peaceful. The staff nurse felt it was important to relay her thoughts which she did. As they sat there together it felt right.....just Molly, her husband and herself. What a privilege she thought to be here with Molly and her husband. Gradually the respirations stop and the nurse gently confirms that Molly has died. Tears well up in his eyes and he pulls out his handkerchief. She doesn't want to leave him so stretches out to ring the buzzer for someone to come. Julie the matron arrives realising what must have happened. She gives Molly's husband a hug . It was a natural thing to do – none of this stiff professionalism - 'feelings' are so important. The night nurse slips out of the room. It seemed a pity that the son and daughter had not been present but in many ways it was fine that it was just Molly and her husband & she was glad she had popped in just at the important time. **[READ page following death of a resident]**

APPENDIX 13a

EVALUATION QUESTIONNAIRE FOR THE IMPLEMENTATION OF THE ICP

I am trying to get as full a picture as possible about how people have found the introduction of the ICP at NH2b. Thank you for taking time to fill out this evaluation. Please feel free to write as much as you can – even using examples if you would like.

1. **From *your* perspective, what ways have you found the 'ICP for the last days of life' helpful in caring for a dying resident?**

2. **What have you found to be difficult about using the ICP?**

3. **What do you see as the advantages/disadvantages of such a tool?**

4. **Please can you comment on how you found the training on the use of the ICP**

5. **What do you see as obstacles to the ICPs continued use at NH2b?**

6. **Any further comments you would like to make about ICPs or the 'end-of-life' project in general – please use this space:**

Thank you very much indeed for taking the time and the trouble to complete the questionnaire. Please return it to me in the pre-paid envelope enclosed as soon as possible. Thanks. Jo Hockley

June 2003

APPENDIX 13b

SEMI-STRUCTURE INTERVIEW OUTLINE
FOLLOWING IMPLEMENTATION OF THE ICP

Hear your thoughts on the ICP – how you feel it works or doesn't work in the nursing home situation. What might obstruct its use as we try and pilot it in other nursing homes.

- From your perspective, what ways have you found the 'ICP to be a useful tool in caring for nursing home residents who are dying?

- In what ways would you say it has improved care?

- What has been difficult about introducing the ICP at [NH2b]?

- Can you see any disadvantages to the use of an ICP in the last days of life?

- Do you think that its use will continue?
    - What do you see as potential obstacles to its continued use at [NH2b]