

**RELATIVES' EXPERIENCES OF
NURSING HOME ENTRY:
A CONSTRUCTIVIST INQUIRY**

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Susan M. Davies

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Summary

Despite growing awareness of the significance of helping a relative to relocate to a nursing home as a key phase in the caregiving career, relatively few studies in the UK have explored this experience in depth. Informed by a constructivist perspective, the study reported within this thesis sought to better understand nursing home placement from multiple perspectives. Using a two stage approach, data were collected from semi-structured interviews with 37 people who had assisted a close relative to move into a nursing home, together with case studies in three nursing homes which explored how relatives are supported in maintaining their caring role in this new context.

Data analysis revealed three phases to the transition: 'making the best of it'; 'making the move' and 'making it better', with relatives' experiences across these phases being understood in terms of five continua, reflecting the extent to which they felt they were: operating 'under pressure' or not; 'in the know' or 'working in the dark'; 'working together' or 'working alone'; 'in control of events' or not, and 'supported' or 'unsupported' both practically and emotionally.

Data from the case studies demonstrated the utility of these factors in understanding the experiences of relatives, residents and staff working in the care homes. In particular, the extent to which carers were able to meet their ultimate goal, that of ensuring 'best care' for their relative was influenced by these factors and the type of 'community' operating in the home.

Analysis identified three types of community within the care homes studied: the controlled community; the cosmetic community; and the complete community. Findings suggest that the 'complete community' is consistent with the most positive experiences for older people, for family caregivers and for staff, and

therefore promotes 'best care'. The ways in which staff, carers and older people can help to forge a complete community are considered.

In addition to providing new insights into the substantive topic of interest the thesis makes a contribution both to methodological debate, and more formal theory, as well as highlighting a number of major implications for policy, practice, education and further research.

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CHAPTER 1. INTRODUCTION

Context and rationale

A sizeable minority of older people alive today are likely to need special support and continuing care as they grow more frail (The Royal Commission on Long Term Care 1999). The chance of living in a long-stay hospital or care home for example, is currently estimated at 5% for people aged 75 – 84 and 21% for those aged 85 and over (Laing and Buisson 2000). While the development of new technologies may increasingly allow older people to remain in their own homes for longer, it is likely that group care in residential and nursing homes will continue to be an important element in the range of care options (Jack 1998). Individuals in need of such care will be amongst the most vulnerable of older people and it is therefore imperative that the support they receive is of the highest quality.

An extensive literature critiquing the nature of long-term care provision for older people has developed during the past 60 years (see for example Townsend 1962, Robb 1967, Willcocks *et al.* 1987). However, this literature says little about the role and needs of family caregivers within the context of long-term care. Most studies of nursing home entry and care have focused on the experience of residents and staff, while the needs of family members at this time have received far less attention. In particular, few studies have gathered qualitative data on relatives' experiences of helping a family member to move into a nursing home and on the ways in which they establish a new role within this context. Temporal models of caregiving, which suggest that family caregivers pass through a series of stages during their caregiving career, are beginning to emerge. These models indicate that when carers assist an older person to move into a nursing home, they enter a new but still involved stage and are likely to require support to achieve a smooth transition (Aneshensel *et al.* 1995, Nolan *et al.* 1996a). However, there is little research evidence to suggest the type of support that will be most effective during

this often difficult period. My main intention in undertaking the study upon which this thesis is based was to develop a deeper understanding of the needs of relatives and family caregivers of older people who move into a nursing home. My main aspiration for the research was that such information would enable nurses and other health care practitioners to better meet those needs.

This chapter presents the background and context for the study and identifies the rationale underpinning the research. It begins with a brief consideration of my motivation for selecting this topic as a focus for my PhD studies and reveals some of the personal assumptions that may have influenced the research. Relevant demographic changes within the United Kingdom (UK) are then outlined, illustrating the challenges facing policy makers and service providers in developing appropriate care services for frail older people and their carers. The response of successive governments to these challenges is then considered through a discussion of key themes apparent within a series of policy initiatives during the latter part of the twentieth century. Subsequently, changes in the conceptualisation of family caregiving over the same period are outlined. Finally, the growing emphasis on user participation in the development and delivery of health and social care services is considered. My intention is to highlight some key issues which may shape the experience of admission to a nursing home. The chapter concludes with the objectives for the research and an overview of subsequent chapters within this thesis. It should be noted at this point that, following this introduction, the available literature and policy developments are considered contemporaneously so that only sources which were available at the start of the study are considered in the initial sections, with more recent additions being reserved for the concluding chapters.

Personal context for the research

The decision to adopt this topic as the focus for my PhD work was prompted by a range of factors. Initially these were predominantly pragmatic, but as the study unfolded I became increasingly engaged with, and committed to, the subject.

Family caregiving for older people emerged as a major focus for research within the School of Nursing and Midwifery at the University of Sheffield following the appointment of Professor Mike Nolan, and he encouraged me to develop the latent interest I had in this area. Subsequently we became engaged in international dialogue about the possibility of comparing relatives' experiences of nursing home entry in three countries. Funding was secured to allow me to undertake some research in the UK on a part-time basis and within this context, the choice of topic might be seen as largely serendipitous. It was only once I had started my exploration of the field that I began fully to appreciate the extent to which the study was consistent with, and built upon, a number of long-held personal and professional commitments.

Throughout my career, both as a health visitor and as a nurse teacher and researcher, I have maintained a particular interest in the lives and needs of older people, which over time has increasingly focused on the needs of older people requiring continuing care. While working within a number of long-stay care wards within the National Health Service (NHS) during the 1980s, I became acutely aware of the poor quality of much of the care delivered within such environments and began to explore alternative approaches to care delivery, both within continuing care and rehabilitation settings (Davies 1992, Davies 1995).

Throughout my early career as a health visitor, I had attempted to work in an empowering way with families and had developed an appreciation of the value of working with *whole* families as well as individuals. More recently, my involvement in a community health development project during the late 1990's (Davies 1999) further stimulated my interest in ways of empowering the users of health care. My commitment to the principle of involving individuals within communities in identifying their own health needs, rather than working to a professional agenda was strengthened. A study focusing on the experiences of relatives who help an older person to move into a nursing home would allow the voices of service users to be heard and potentially influence professionally led agendas for service delivery. At the same time such a study would enable me to explore further the significance

and contribution of family relationships to residents' quality of life. Moreover, undertaking a PhD study in this area would contribute to the knowledge base for practice in continuing care - a hitherto relatively neglected area for nursing research within the UK, which as the demographic changes suggest, is likely to be of increasing importance.

Demographic changes and challenges

Consistent with countries across Europe, the average age of the population of the UK has been steadily increasing. The long-term trends of lower birth rates, improvements in health status and rising longevity have combined to produce a constant growth in the proportion of the population who are aged 60 years and over (OECD 1994). However, these changes have not been consistent across different age groups, with the most rapid recent changes being apparent among those aged 80 and over. This latter group, who generally have far higher levels of disability secondary to multiple chronic diseases, will present particular challenges to health and social care systems.

It is important to recognise that even amongst the very old, only a minority require institutional care, the majority being cared for in the community with family support (Walker 1995). Nonetheless, an ageing population does present a series of challenges for policy makers, partly because of the association between disability (including dementia) and advanced old age, and partly because of changes in the household situation of older people. As Sundstrom (1994) points out, the ways people live together have fundamental implications for patterns of giving and receiving care. The growth in solitary living, the decline in co-residence between generations and the increase in women's employment outside the home are all impacting on families' ability to provide informal networks of support for older people who need help to remain in the community (Commission of the European Communities 1996). Most importantly, the trend towards smaller family size has resulted in a reduced number of potential caregivers compared to those needing care. Changes in family structure resulting from increased geographical mobility

and the impact of divorce are also influencing the availability of family support (Victor 1991, Coleman *et al.* 1993). Consequently, families are facing the prospect of caring for older relatives for longer, with fewer potential family members to help. Without adequate support, these caring relationships are likely to break down, resulting in increased demand for continuing care. Therefore, whilst a policy of community care might be the objective of countries across Europe (Davies 1995), there will always be a need for alternatives (Victor 1997), and this raises a number of tensions.

Tensions between continuing care and community care: some themes and consequences

A number of themes can be traced through policy initiatives in the UK during the late 20th century that have shaped the current experiences of older people living in care homes and their family caregivers. Davies (1995), one of the architects of community care in Britain, argues that, despite differing welfare systems, countries across Europe share three common policy objectives in relation to older people:

- ◆ an emphasis on enabling people to be cared for in their own homes or in a homely environment within the community;
- ◆ increased reliance on family and other sources of support and care;
- ◆ an emphasis on reducing the cost of care to public funds.

(Davies 1995)

In the UK, community care has been a long-standing aim of successive governments for several decades but it became a more explicit policy initiative at the end of the 1980's with the publication of the White Paper: *Caring for People* (DoH 1989). This gave a far fuller description of the aims of community care policy, with these being to:

- ◆ promote the development of domiciliary, day and respite services to enable people to live in their own homes wherever feasible and sensible;
- ◆ ensure that service providers make practical support for carers a high priority;
- ◆ make a proper assessment of need and good care management the cornerstones of high quality care;
- ◆ promote the development of a flourishing independent sector alongside good quality public services;
- ◆ clarify the responsibilities of agencies and so make it easier to hold them to account for their performance;
- ◆ secure better value for taxpayers' money by introducing a new funding structure for social care.

The NHS and Community Care Act (DoH 1990), which followed the White Paper, introduced a contract culture to arrangements for funding continuing care. In brief, this involved a system of assessment and case management, with social services departments purchasing packages of care from a range of service providers across the private and voluntary sectors as well as statutory services. The stated emphasis was on users and carers as consumers and the Act was intended to increase flexibility and consumer choice as well as giving greater recognition to the needs of family caregivers. However, as an unintended consequence of the Act the role of continuing care became increasingly ambivalent, with admission often being seen as a failure of community care. This reinforced the already growing public perception of entry to care as being the 'final sign of failure' (Victor 1991) rather than the 'positive choice' it was once envisaged to be (Wagner 1987). Paradoxically, therefore, despite the avowed intention of the NHS and Community Care Act

(1990) of increasing choice and involvement, a number of factors effectively combined to reduce real choice about entry to institutional care. These include:

- ◆ the ‘tarnished’ image of institutional care in both the academic literature and the popular media (Victor 1991, 1997), which has perpetuated a view of such environments as being ‘universally dysfunctional’ (Higham 1994);
- ◆ the continued uncritical acceptance of the implicit assumption underpinning community care that living at home is inherently superior to communal alternatives (Willcocks *et al.* 1987, Peace 1998). While this may have intuitive appeal there have been virtually no studies that have compared the quality of life between the community and care homes among equally frail populations (Baldwin *et al.* 1993). Indeed there is some evidence to suggest that very frail older people living at home may have an unacceptably low quality of life (Lawton *et al.* 1995a);
- ◆ the new funding arrangements following in the wake of the NHS and Community Care Act (DoH 1990) which introduced eligibility criteria based on dependency, effectively precluding admission for other reasons (for example, the desire for company or a secure environment) unless older people were self-funding.

As a result of the above, admission to care has become increasingly ‘crisis’ driven, thereby substantially reducing the time available for constructive decision-making. This, as will be apparent from the literature (see Chapter 2), has exerted a number of negative effects on the admission process.

Support for family caregivers: changing concepts and policies

In reality, care in the community is provided predominantly by family members, usually spouses or children and most often women. Walker (1995), for example, estimates that 80% of the care required by frail older people in Europe is provided

by the family. Unfortunately, services for family caregivers have been poorly developed and motivated mainly by instrumental objectives; that is, services are provided primarily to keep carers caring (Twigg and Atkin 1994). Evers (1995) suggests that there is a need to move towards systems of formal support which complement and supplement, rather than substitute, family care. This will require sensitive assessment processes that recognise that family caregivers have legitimate needs of their own, and a rethinking of the aims of supporting such caregivers. More generally, there have been calls for a broader conceptualisation of the aims and rationale for supporting carers. A symposium held at the World Congress of Gerontology in 1997 for example concluded that carer support should be defined as any action which assists carers to: decide to take up (or not to take up) a caring role; carry on in a caregiving role or decide to give up a caring role (Askham 1998). The latter aim suggests a conscious, informed and supported decision to seek alternative caring arrangements which, from the literature available at the start of the study, did not seem to be the case (see Chapter 2).

Debates about the aims and purposes of supporting family caregivers can also be discerned in the policy literature as, despite the avowed intention of placing carers' needs high on the policy agenda, it became increasingly apparent that the NHS and Community Care Act did little to improve the support carers received. Dissatisfaction with existing arrangements and intensive political lobbying resulted in the passage of a Private Members Bill and the placing of the Carers (Recognition and Services) Act on the statute books (DoH 1995).

This Act, for the first time, afforded carers a statutory right to a separate, although not independent, assessment of their own needs. The practice guidance that accompanied the Act (SSI 1996) identified the principles of a carer's assessment, stressing the need to start from the carer's perspective, to identify their strengths, weaknesses and coping resources, and to offer early interventions. Importantly the Act also differentiated between '*care for*' (the physical components of care) and '*care about*' (the emotional aspects of care) and stressed the need to focus on both the carer's ability and willingness to care. The potential usefulness of this

framework was, however, reduced by the inclusion of eligibility criteria which limit an assessment under the Act to carers who provide 'regular and substantial' care. This confounds the need for support with the amount of care given, an assumption which is not supported by the majority of empirical research into the caregiving situation (see Nolan *et al.* 1996a for a review).

Consequently, while the Act suggests the potential for an holistic consideration of carers' needs, in practice assessments still tend to focus on physical rather than emotional needs (Fruin 1998) and there is a general consensus that the Act has not achieved its full potential (Henwood 1998). There is also evidence to suggest that the principles of user and carer involvement are not being fully implemented at the time of admission to permanent care (Audit Commission 1997). Locally an analysis of Full Needs Assessments (FNA) carried out on behalf of Sheffield Family and Community Services in 1997 found that family carers' perceptions of their relative's needs or of their own needs were rarely indicated explicitly (Appendix I). This reinforced the conclusion that the emerging emphasis on user and carer participation in service design and delivery, another prominent trend at the start of the study, was more rhetorical than real.

Participation in care: service users as partners in care

Service user participation in care planning and delivery is now a widely accepted principle underpinning health and social care policy, although commitment to the concept in practice has been questioned (Williamson 1992, Kendall 1993, Meyer, 1993). However, there is evidence that many social care professionals are beginning to dispute traditional models of training which emphasise professional autonomy and are seeking ways of working which are less oppressive and more open to user involvement (Mullender and Ward 1991, Walker and Warnes 1996). Walker and Warnes (1996) for example call for a change in professional values and attitudes within the formal sector so that co-operation and partnership with users is regarded as a normal activity. They identify a number of organisational principles and structures which militate against user-participation in service planning and

delivery, in particular those which encourage professionals to regard themselves as 'experts'. Participation in care necessarily involves a change in relationships between professionals and lay people, whether they are patients, residents or family caregivers (Kirk and Glendinning 1998). This requires a sharing of professional knowledge which professionals may find threatening (Trnobranski 1994). Some recent work has attempted to access user views and feed these directly into the commissioning process for continuing care (Barnes and Walker 1996, Mitchell and Koch 1997, Raynes 1998). However, for many older people and family caregivers, conditions do not yet exist which would facilitate active participation in decision-making in health care. This can often result in a tokenistic approach to user participation which fails to realise the true potential for either service users or providers. Admission to care, one of the last major decisions that an older person might make, represents a genuine 'test' for partnership working. It was against such a context that the present study emerged, and the initial objectives of the research were developed.

Objectives for the research

If the changes and challenges outlined above are to be addressed, it seems likely that new models of working with older people and family caregivers will be needed. In developing these approaches it is crucial that the voices and experiences of older people, their relatives and family caregivers are heard and accounted for. With these factors in mind the following broad objectives informed the commencement of the study:

- ◆ to explore, describe and interpret the experiences of family caregivers in relation to helping a relative to move into a nursing home and continuing to support them within that setting;
- ◆ to explore, describe and interpret current practice within nursing homes in relation to supporting and involving family caregivers, particularly around the time of admission;

- ◆ to integrate and critically analyse data from the perspectives of family caregivers, residents of care homes and staff to identify consistencies and inconsistencies;
- ◆ to generate understandings and insights to inform, assist and empower people who experience admission to a nursing home in the future;
- ◆ to generate publications and debate to inform and improve the practice of health professionals, particularly nurses working both in hospitals and nursing homes.

Following consideration of the literature, a qualitative study was designed (see Chapter 3) to meet the above research objectives. The challenges encountered in using the chosen methodology (constructivism) are fully discussed in an attempt both to inform other researchers in the field, and to contribute to the debate on approaches to the collection and analysis of qualitative data within an empowering framework. Synthesis of findings from the study with existing literature suggests a number of recommendations for practice, policy, education and further research in this field.

This thesis provides an account of the above ‘journey’ and is organised as follows:

Chapter 2: sets a context by briefly considering key themes from the extensive literature on family caregiving before turning to a more focused analysis of experiences of admission to a care home. Literature from the perspectives of family caregivers, older people and service providers is reviewed in order to highlight roles and relationships within continuing care settings.

Chapter 3: describes the methodology for the study. The rationale for adopting a constructivist approach, operationalised within a two-stage methodology, involving qualitative interviews with a sample of relatives followed by case study research in

three nursing homes, is explored. Methods and techniques for the collection and analysis of data are described.

Chapter 4: here, findings from 37 semi-structured interviews involving 48 relatives of older people who had moved into a nursing home are described. Key themes are analysed and a tentative model of roles and relationships is presented.

Chapter 5: presents within-case analyses from case study research in three nursing homes. This is followed by a cross-case analysis comparing and contrasting themes emerging across the three homes. This chapter concludes with a framework describing a range of 'communities' within continuing care settings which appear to exert an important influence on how life and work in the homes is experienced.

Chapter 6: begins with a reflective account of the methods used within the study. Findings from both phases of the study are then synthesised and integrated with the substantive literature in this field, including both items considered within the initial literature review and items appearing during the last two years. Theoretical perspectives are explored and, in moving from a substantive to a formal focus, the study findings are compared with the mid-range theory of nursing transitions expounded by Meleis *et al.* (2000).

In **Chapter 7**, the policy context is updated and implications of the study findings are discussed with reference to practice, policy, education and research in the field of long-term care for older people. These cover decision-making in long-term care, the provision of appropriate care and care environments, and the preparation of staff involved in assisting older people and family caregivers to make a smooth transition to nursing home care.

It is hoped that the findings and implications of this research will be of particular value to older people, to family caregivers and to anyone involved in supporting them within the caregiving relationship.

CHAPTER 2. PRELIMINARY REVIEW OF RELEVANT LITERATURE

Introduction

Given the study's focus on experiences and perceptions, it was anticipated that the methodology used would be predominantly qualitative and that research findings would emerge primarily from the data rather than being shaped by existing theory. The use of literature within qualitative research is a contested area. Some authors (see for example Glaser and Strauss 1967) argue that no literature should be consulted prior to commencing fieldwork, in order to avoid biasing data collection and analysis. Others (Strauss and Corbin 1990, Morse 1994) argue that an overview of relevant literature is essential. Morse suggests that a preliminary review of the literature allows the researcher to '*recognise leads without being led*' (Morse 1994 p27). Strauss and Corbin (1990) suggest that literature should be used within qualitative studies to:

- ◆ stimulate theoretical sensitivity to certain recurring and apparently important themes and concepts that may be looked for in the data;
- ◆ stimulate interview questions and observation;
- ◆ provide ideas for directed sampling;
- ◆ help validate any developed theory.

(Strauss and Corbin 1990)

Within this study, a preliminary review of relevant literature was considered necessary for three main reasons. Primarily, I felt it was essential to have a broad 'feel' for the literature in the field of continuing care, in order to inform my understanding of the context for the study. Secondly, a consideration of the

literature on family caregiving would help to locate the move to nursing home care within a temporal perspective. Finally, I wanted to identify key issues within the literature on families' experiences of nursing home entry in order to inform data collection and to identify potential sensitising concepts (van den Hoonaard 1997). With these objectives in mind, the initial review of the literature was guided by a consideration of three broad areas:

- ◆ experiences of family caregiving and decisions about nursing home entry;
- ◆ the nursing role in assisting older people and family caregivers to move into a nursing home;
- ◆ the role and experiences of older people and family caregivers within the care home setting.

Methods and boundaries

In order to identify relevant literature, electronic databases were searched for the time period 1988 - 1998. Details of the databases searched are shown in Figure 2.1.

I decided initially to limit the search to the most recent ten years and to reconsider this timescale on the basis of the volume of literature identified. This strategy would also focus on the literature which has emerged since the large-scale shift of continuing care from NHS hospitals into the private sector within the UK. Given the number of references identified from this initial search (see below), the timescale was deemed appropriate. However, these references were also supplemented using an incremental approach whereby key items cited within references were added if they had not already been identified.

Search terms included: relatives, family carers, family caregivers, admission, nursing, nursing practice, nursing homes, residential homes, elderly, aged, older people, long-term care and continuing care. This process resulted in the

Figure 2.1 *Electronic databases consulted for the review*

CINAHL	The Cumulative Index to Nursing and Allied Health Literature.
MEDLINE	Encompasses information from Index Medicus, Index to Dental Literature and international nursing literature.
PSYCHLIT	Covers international literature in psychology and related fields.
BIDS	Provides access to four bibliographic databases supplied by the Institute for Scientific Information, covering scientific and technical information, social science, arts and humanities. <i>I searched the social science database.</i>
AGEINFO	The database compiled by the Centre for Policy on Ageing.
HMIC	Health Management Information Consortium brings together three complete bibliographic databases covering UK and overseas health management and related topics. These are: The Department of Health Library, the Nuffield Institute for Health Database and the King's Fund Database.

identification of more than two thousand references, full bibliographic details of which were entered into an Endnote library (Endnote Version 3.0, Niles Software 1988). Endnote is an electronic referencing tool combining the functions of database management and bibliography creation. It stores and allows easy searching of references and can be customised to create fields identified by the user. Finally, it can also be used to insert citations into word processing documents and create bibliographies in any required format. Endnote provided a

valuable tool, not only for sorting references but for storing information extracted from each item in the process of literature review and evaluation.

The majority of the items identified by the initial searches were academic and professional papers in peer reviewed journals, with books and reports contributing approximately 5% of the total. Initially, the title, keywords and abstract for each of these references was examined. References which were felt to be particularly relevant to the study were identified and selected on the basis of the following criteria:

- ◆ they described the experiences of older people and/or family caregivers around, and following, the period of the move to a care home;
- ◆ they described structures and processes likely to impact upon the experiences of older people moving into care homes and their family caregivers.

This process resulted in the initial identification of 220 items. All of these were considered, but only about 20% related specifically to the needs of family caregivers in relation to nursing home entry, confirming the relative emphasis within the literature on the experiences of older people and staff. All 220 items were retrieved and reviewed using a systematic approach. After Cuba (1993) and Depoy and Gitlin (1993) the following information was extracted for each item and recorded within the Endnote database:

- ◆ key themes within the paper, including theoretical and conceptual frameworks drawn upon within the work;
- ◆ the major objectives of the paper or the questions posed in the study;
- ◆ the methods of investigation;

- ◆ the boundaries of the paper (for example the study population and sample, or the limits of a literature review);
- ◆ the main findings;
- ◆ the author's conclusions and recommendations.

Additionally, the reference list for each item was examined and any items which appeared to be particularly relevant to the study were added to the database and retrieved. The list of themes generated using this approach was considered and themes were grouped under major headings. These headings represent the scope of the literature reviewed at this stage of the study and provide the structure for this chapter. Key themes and issues relating to the experiences of relatives and residents, both at the time of admission and afterwards are reported. The main themes are:

- ◆ experiences of family caregiving over time;
- ◆ tensions in decision making about long-term care options;
- ◆ the needs of family caregivers for information and support during the transition to a care home and afterwards;
- ◆ experiences of life in a care home for older people and family caregivers including:
 - difficulties in maintaining relationships
 - vulnerability and powerlessness
 - isolation and exclusion;
- ◆ the potential for family caregivers to impact upon the quality of life for older people living in care homes;

- ◆ current practice in relation to supporting family caregivers within the care home context.

In relation to each broad theme, individual items are compared and contrasted in order to identify key findings and their implications. A summary then highlights the key issues which informed data collection and analysis within the study.

A temporal perspective on family caregiving

The last twenty years have witnessed a huge increase in the volume of research on family caregiving (George 1994). The majority of this work has focused on the difficulties and burdens of care and has resulted in considerable insights into these aspects (Twigg and Atkin 1994). The detrimental effects of caregiving on caregivers' physical and mental health, relationships and economic circumstances have been repeatedly demonstrated. Broadening the perspective, models of caregiving have been developed over time which reflect the social and emotional dimensions of care as well as the physical and practical (Bowers 1988; Nolan *et al.* 1996a). Support mechanisms which can enable family caregivers to continue to care have also been identified, but these have been informed largely by a '*pathological perspective*' which has focused largely on stress reduction (Twigg and Atkin 1994).

More recently, there has been a growing awareness of the potential sources of satisfaction and reward in family caregiving (Kobayashi *et al.* 1993, Langer 1993, Cohen *et al.* 1994, Levesque *et al.* 1995, Nolan *et al.* 1996a). On the basis of a grounded theory study, Kobayashi *et al.* (1993) for example describe the personal growth and evolving expertise enjoyed by family carers throughout the continuum of care. Nolan *et al.* (1996a) also highlight the pervasive and diverse nature of rewards that carers may experience. They identify three main sources of satisfaction, deriving from the relationship with the cared-for person, from the orientation of the carer to care, and from the desire to promote positive outcomes and avoid negative outcomes for the cared for person. In a similar vein, Cartwright *et al.* (1994) describe the concept of caregiving enrichment, which is

defined as '*the process of endowing caregiving with meaning or pleasure for both caregiver and care recipient*' (Cartwright *et al.* 1994 p33). Consideration of the intrinsic meaning and rewards of caregiving is essential to an understanding of the experiences of relatives at the time of relinquishing the major caregiving role.

It is now increasingly appreciated that the way caregiving evolves over time is important and that a longitudinal perspective is needed to inform policy developments, service interventions and professional practice (Wilson 1989, Naleppa 1996, Nolan *et al.* 1996a). The most sophisticated temporal models of family caregiving have been developed in the field of dementia care. Wilson for example (Wilson 1989) explored the experiences of 20 family caregivers caring for people with dementia and describes an eight-stage model. The final stage, *turning it over*, represents the gradual realisation that the carer's own physical and mental health are suffering and that alternative care arrangements are necessary (Nolan *et al.* 1996a). Wilson acknowledges that most carers continue to play an active, if modified role, after admission.

Based on a distillation of the literature and several years of empirical research, Nolan *et al.* (1996a) refined and adapted Wilson's model to reflect a range of family caregiving situations. They identify six stages:

- ◆ building on the past - recognising the foundations of the caregiving relationship;
- ◆ recognising the need - acknowledging that the nature of the relationship with the cared-for person is changing;
- ◆ taking it on - weighing up the options and making a decision to assume the caregiver role;
- ◆ working through it - the day-to-day work of keeping going and finding some balance and meaning in their situation;

- ◆ reaching the end - either because the cared-for person dies or their circumstances change so the need for alternative caregiving arrangements is acknowledged;
- ◆ a new beginning - the carer establishes a new caregiving role or re-builds his or her life in the absence of the cared-for person.

Nolan and colleagues (Nolan *et al.* 1996a) suggest that these stages are not meant to be interpreted rigidly nor applied in a mechanistic or linear fashion but rather they serve to identify key transition points that occur in caregiving over time and help to highlight factors which influence decision-making. An understanding of these factors will help practitioners to identify appropriate interventions to support family caregivers at each stage.

Within the context of this study, the final two stages in the caregiving trajectory are particularly relevant, with the process of decision-making in relation to alternative long-term care arrangements providing an important focus for supportive interventions. A growing body of evidence suggests that the decision to move into a care home is increasingly precipitated by an acute health crisis (Allen *et al.* 1992; Hunter *et al.* 1993; Dellasega and Mastrian 1995; Bell 1996, Centre for Policy on Ageing 1996, MacDonald *et al.* 1996). A study reported by Victor (1997) for example indicated that up to 80% of admissions follow a 'devastating change in health status'. However, there is also evidence to suggest that decision-making for nursing home placement is a process that begins early on in the caregiving career (Pruchno *et al.* 1990, Cosbey 1994). A longitudinal study of 220 spouse caregivers (Pruchno *et al.* 1990) found that the single best predictor of placement was the desire to institutionalise at baseline. This suggests that an acute episode may act as the trigger which finally prompts the family to commit to the decision. Other commentators have also described the transition to new long-term care arrangements as a process rather than a single event (Gonyea 1987, Fink 1995). Gonyea for example (Gonyea 1987) describes a process consisting of four stages: recognition, discussion, implementation and placement.

There is no doubt that the period of decision-making is a difficult time for most carers and cared-for persons, but one that is relatively poorly understood. Most studies of the move to a care home have examined the perspective of the older person themselves (see for example Reed and Payton 1995, Reinardy 1995, Morgan *et al.* 1997, Wilson 1997) with the experiences of family caregivers at this time being relatively under-explored. However, it is clear from the limited literature that a number of competing tensions render the process of decision-making about long-term care options extremely difficult for many family caregivers. These tensions are explored within the next section.

Tensions in decision-making about long-term care options

The literature reveals a number of competing and conflicting factors which both prompt and militate against the decision to place a relative in a care home. In terms of drivers towards admission, the existence of additional stressors such as incontinence and wandering behaviour on the part of the cared-for person, reduced caregiver resources and caregiver perceptions of burden have all been associated with the decision for placement (Pruchno *et al.* 1990, McFall and Miller 1992, Naleppa 1996). In a review of studies published between 1989 and 1995, Chenier (1997) identified decreased functional abilities of the care receiver, interrupted sleep of the caregiver, and the presence of multiple stressors within the caregiving situation as positively correlated with caregiver burden and increased risk of nursing home placement.

Increasing dependency and frailty of the cared-for person are generally considered to be important factors influencing admission to a care home (Gonyea 1987, Johnson *et al.* 1994). There is some evidence to suggest that the need to assist an older relative with intimate care tasks as a result of functional dependence may violate norms concerning appropriate family roles and interactions (Gonyea 1987) and that this prompts the decision for placement in some cases. However, a retrospective study of homecare users who had transferred to a nursing home found that caregiver problems, such as living apart from the relative and the need to balance caregiving with paid employment, were more important predictors of

nursing home placement than functional ability (Tsuji 1995). Importantly, lack of satisfaction in caregiving has also been associated with nursing home placement (Pruchno *et al.* 1990).

Other important influences may be found outside the caregiving relationship. Wright's interview study of 67 relatives of older people living in nursing homes in the UK for example found that a lack of flexibility in community support services was an important factor in the placement decision (Wright 1998). Pressure to release a hospital bed has also contributed to the decision in some cases (Clemens 1995, Wright 1998).

Opposing these various 'drivers' towards institutional placement are the almost universal feelings of hostility and negativity which admission to care engenders among both older people and their carers (Jani-le-Bris 1993). Care homes are commonly perceived as alienating places where older people go to die - 'the end of the line' (Nay 1995). Furthermore there is a perception that individual rights are likely to be subsumed by institutional routines and regulations (Levine 1995). In light of the recent shift of long-term care into the private sector, nursing home owners are often seen as profiting from an 'aged care industry' and are perceived not to have the best interests of residents at heart (Anson 1995).

Views of the older person may also be an influencing factor and many individuals are likely to be resistant to the idea of moving into a care home. The perception of the potential loss of personal autonomy is an important factor here: in a survey of preferences for continuing care, loss of control was cited as the main reason participants would not choose entry to a care home as a preferred care option (Kelly *et al.* 1998). While for some older people entry to care can be a 'positive choice' (Allen *et al.* 1992, Nolan *et al.* 1996b), this appears to be the exception, with admission to care being described as an 'unavoidable spectre' in later life (Biedenharn and Normoyle 1991), and being associated with the end of 'independent life' (Lewyeka 1998). As a consequence there is often extensive psychological and emotional resistance to the idea of entering care (Roberts *et al.* 1991).

Older people themselves often perceive that others have made the decision for them to move into a care home (Johnson *et al.* 1994, Nay 1995). This also applies to family members, with the role of an authority figure such as a doctor in instigating the decision highlighted in a number of studies (Morgan and Zimmerman 1990, Naleppa 1996). For relatives in particular, the almost universally negative images of nursing homes may contribute to a reluctance to accept ultimate responsibility for the decision.

In reality, each caregiving situation is unique and the decision for nursing home admission is likely to result from a complex interplay of factors (Groger 1994). Given the personal conflict that is frequently created by the final decision, information and support are essential.

The needs of family caregivers for information and support during the transition to a care home

Whatever the circumstances of admission to a care home, family caregivers are increasingly expected to play a significant role, both in the initial decision about the need for care, and subsequently in selecting an appropriate home (Nolan *et al.* 1994a, b, Dellasega and Mastrian 1995, Nolan *et al.* 1996b, Dellasega and Nolan 1997, Sulman *et al.* 1996, McAuley *et al.* 1997). Due to the rise in emergency admissions and shorter lengths of hospital stay within the UK, especially amongst older people (Audit Commission 1997), the time available for placement decisions is often limited (Dellasega and Nolan 1997, McAuley *et al.* 1997, Wright 1998). However, far from receiving adequate support during this period of 'crisis escalation' (Dellasega and Mastrian 1995), the assessment of carers' needs appears to be poorly developed (SSI 1996, Audit Commission 1997). Although this has been recognised for some time (Buckwalter and Hall 1987, Pratt *et al.* 1987), recent legislation, such as the NHS and Community Care Act (DoH 1990) and the Carers Act (DoH 1995), seems to have had little impact on practice. Relatives report feeling pressurised to accept hospital discharge dates (Relatives Association 1994) and describe the process of finding a home as 'hectic and stressful' (McAuley *et al.* 1997). There is some evidence to suggest that, once the decision

that nursing home placement is needed has been made, older people and their carers receive relatively little attention (Sulman *et al.* 1996, Reed and Morgan 1998). Cotter *et al.* (1998) attribute this to the fact that nurses feel unprepared to deal with the distress created by the decision and therefore concentrate on completing the bureaucratic process rather than conducting an holistic assessment of need.

The period leading up to admission to a nursing home is often particularly difficult for family caregivers, most of whom will never have had to make such decisions, or select a nursing home, before (Aneshensel *et al.* 1995). The difficulties that carers experience are further compounded by the lack of information they receive. This has been a consistent finding in several studies (Roberts *et al.* 1991, Allen *et al.* 1992, Hunter *et al.* 1993, Dellasega and Mastrian 1995), and it is apparent that, despite advances in technology, information giving remains problematic (Audit Commission 1997, McAuley *et al.* 1997, McDerment *et al.* 1997). Carers frequently receive little advice and guidance, with information usually being limited to a simple list of homes (Nolan *et al.* 1994a, SSI 1996). Rarely are they given any explicit help in terms of criteria for selecting a home and their understanding of the financial implications of placement is often minimal (Nolan *et al.* 1994a, b).

Although it is widely advocated that alternatives to nursing home placement are explored thoroughly, together with the advantages and disadvantages of entry to care (CPA 1996, Lewyeka 1998), this is often not the case. Indeed exploration of other options is frequently not encouraged (Myers and MacDonald 1996), possibly because few genuine alternatives exist (Audit Commission 1997, Wright 1998). Moreover, while there may be growing recognition of the emotional consequences of entry to care for both older people and their carers, staff are often unsure how to respond and are in many cases constrained by time pressures (Cotter *et al.* 1998, Reed and Morgan 1998). The complex and ambivalent emotions carers experience during the placement process noted previously are frequently not addressed (Lewis and Meredith 1989, Roberts *et al.* 1991, Nolan *et al.* 1994a, b), and even if carers

voice their concerns they feel these are 'heard but not listened to' (Sulman *et al.* 1996, Cotter *et al.* 1998).

The previously described lack of information about homes, combined with the limited criteria on which carers have to base a judgement, also limits the extent to which alternative homes are explored. The pressure to vacate beds identified earlier means that carers often take the first available place. Alternatively, they may base their selection on relatively superficial criteria such as appearance or decor (McAuley *et al.* 1997) or 'informal knowledge', for example, local reputation, proximity or prior experience by peers, family or friends (Nolan *et al.* 1994a, b, McAuley *et al.* 1997). McAuley *et al.* (1997) suggest that with the benefit of hindsight many carers would apply a more discerning set of criteria before selecting a home, including quality of care, range and type of activities, and staffing levels and qualifications. The nature of the search and selection process is forcefully summarised by McAuley *et al.* (1997) who, on the basis of interviews with 28 nursing home 'sponsors' suggest that professionals expect family carers to:

'Navigate very complex systems of health and social care, even though these lay individuals usually have minimal or no experience with, or understanding of, the policies, processes and services they encounter.'

(McAuley *et al.* 1997 p237)

Family caregivers are faced with these practical challenges at a time when they are also attempting to deal with a wide range of conflicting emotions. Numerous studies have identified admission to a residential or nursing home as a major life event, both for older people and their family carers (CPA 1996, McAuley *et al.* 1997, Morgan *et al.* 1997, Ross *et al.* 1997). It has been described as one of the most difficult of life's decisions (Lewyeka 1998), often a brutally abrupt event (Vesperi 1995) and may represent one of the most unhappy periods in family life (Buckwalter and Hall 1987). While it is important to recognise that this is not necessarily a stressful period for all older people and carers, some anticipatory

stress is almost universal (Aneshensel *et al.* 1995) and carers in particular experience a complex range of ambivalent emotional reactions (Allen *et al.* 1992, Ade-Ridder and Kaplan 1993, Dellasega and Mastrian 1995). Typically there are feelings of relief, which are usually coloured by emotions such as guilt, shame, sadness and a sense of failure (Allen *et al.* 1992, Ade-Ridder and Kaplan 1993, Aneshensel *et al.* 1995, Dellasega and Mastrian 1995, Nolan *et al.* 1996b, McAuley *et al.* 1997, Lewyeka 1998).

Several studies have highlighted the need for nursing home staff to be made more aware of relatives' needs, both at the time of admission and subsequently (McDerment *et al.* 1997, Pillemer *et al.* 1998). Family members experience loss and grief, following the admission of their relative and report that these emotions continue throughout the time that the older person remains in the nursing home (Johnson 1990, Dellasega and Mastrian 1995, Tilse 1997). Contrary to popular perceptions, most relatives wish for continued involvement following admission (Bogo 1987) providing opportunities for staff to offer support.

There are suggestions that admission to a care home should not be viewed as a failure but rather as a logical, and in some cases inevitable, phase in the caregiving career (Aneshensel *et al.* 1995). A clear understanding of the placement process is therefore essential in order to consider how this can be made as positive as possible for both the older person and, where relevant, family caregivers. There is no doubt that older people experience profound psychological and physical effects on moving into a care home and these effects are likely to impact upon family caregivers. However, there is evidence that the move can be perceived positively if planned carefully with the involvement of the older person and their family (Nolan *et al.* 1996b, Pearson *et al.* 1998). Studies of admission to a care home have identified the need for continuity of care planning between care settings and there are suggestions that better comprehension of what happens to older patients across organisational boundaries may facilitate continuity of care (Anderson and Helms 1994, Cotter *et al.* 1998).

Nolan *et al.* (1996b) suggest that the type of admission experienced by an older person and their family caregivers is influenced by four sets of processes (Figure 2.2.). These processes shape the experiences of older people and their families both around and beyond the point of admission to a care home.

Figure 2.2 Processes influencing admission to a care home

Anticipation - the extent to which the admission is planned in a proactive way, with discussion occurring well before decisions are needed.

Participation - the extent to which both the older person and their carer(s) are involved in the decision-making process.

Exploration - in three main areas:
(a) alternatives to admission to care
(b) of feelings towards admission
(c) of a number of possible homes

Information - the extent to which older people and their carers received sufficient information on which to base an informed choice.

(Nolan *et al.* 1996b)

Nolan *et al.* (1996b) also describe four types of admission (Figure 2.3) which they suggest represent the range of experience when older people are admitted to a care home. These range from the positive choice (seen as the ideal) through the rationalised alternative and the discredited option to the *fait accompli*. In support of this framework, a number of authors have demonstrated the importance of planned admission involving the older person and their family caregivers as far as possible (Nay 1995, Iwasiw *et al.* 1996, Wilson 1997). Iwasiw *et al.* for example (Iwasiw *et al.* 1996) interviewed twelve new residents of five nursing homes and found that those who had felt actively involved in the decision to be admitted found their adjustment to care was easier. A qualitative study of ten families who had recently placed a relative with Alzheimer's disease in a nursing home identified a number of factors which appeared to ease the period of transition (Morgan and Zimmerman 1990). These included the availability of emotional support, a sense that the decision was shared and feeling in control of the situation. However, in four separate studies exploring over 70 admissions, together with focus groups eliciting perceptions of the prospect of admission to care from older people, Nolan *et al.* (1996b) found that anticipation was a rare feature and that, in most instances, participation, exploration and information did not figure as prominently as they might.

It has been recognised for some time that admission to care is rarely anticipated in advance (Lawrence *et al.* 1987), with there being little evidence of a proactive and planned approach (Lawrence *et al.* 1987, Allen *et al.* 1992). This is largely a consequence of the negative perceptions of institutional care noted earlier, with Victor (1997) suggesting that nearly 60% of family carers totally reject the idea of admission to care. Due to such taboos carers rarely discuss the possibility openly with the person they care for (McAuley *et al.* 1997, Lewyeka 1998), so that when decisions are needed they have little information on which to base a judgement (Aneshensel *et al.* 1995, McAuley *et al.* 1997).

Assessments during this period are often 'convoluted' (Nolan *et al.* 1994a) or fragmented and confusing (Cotter *et al.* 1998), with a lack of coordination and

Figure 2.3 Ideal types of admission to a care home

The positive choice

Characterised by at least some consideration of when to enter care, where to enter care or which home to choose. The older person is either a senior or equal partner or control is handed over following full discussion. An opportunity had been afforded to explore alternatives to care, feelings and perceptions about potential admission and the type of home considered appropriate. Opportunities exist to maintain a sense of continuity.

The rationalized alternative

Involves less anticipation, participation, exploration or information than the positive choice. The move is not seen to be desirable per se: however, the older person is able to create and sustain a perception that the admission is legitimate and/or reversible. Older people sometimes turn the admission into an altruistic act on their behalf, rationalizing that they have taken the decision for their carer's benefit. Alternatively, the older person may realise that they are too frail to manage at home and, particularly if the move has 'official sanction', usually from a doctor, this allows for a rational and reasonable explanation for the move to be constructed.

The discredited option

The discredited option usually began life as either a positive choice or a rationalized alternative but shortly after admission the situation changes and initial perceptions are in some way 'spoiled'. For example, the older person has been promised a single room and then has to share, or has been informed that other residents are lucid when a majority are cognitively impaired. Alternatively older people may enter care with false beliefs about the reversibility of the move or expecting a rigorous treatment regime when none is available. Such events can sour initial expectations and create a legacy of mistrust and resentment.

The fait accompli

The 'worst case scenario' in which virtually all the basic conditions for an acceptable move into care are absent. There is no anticipation, the decision is generally taken by others, and there is no opportunity to explore alternative options, emotional reactions to the move or to select a particular home. There is a lack of good quality information. In such circumstances the move is usually perceived in entirely negative terms with no basis on which to create a positive or rational explanation.

(Adapted from Nolan *et al.* 1996b)

adequate documentation (Audit Commission 1997). It is apparent that older people themselves frequently do not figure prominently in the decision-making process and often do not have the opportunity to visit the home before moving in (Allen *et al.* 1992, Hunter *et al.* 1993, Myers and MacDonald 1996, Audit Commission 1997, Brown 1998, Cotter *et al.* 1998, Reed and Morgan 1998). Analyses of the care management process indicate that real choice is often absent (Myers and MacDonald 1996, Audit Commission 1997), with particular criticisms being apparent in respect of finding a residential or nursing home place (Myers and MacDonald 1996). And yet the selection of a home is crucial: on the basis of longitudinal interviews with 46 older people before and after the transition to a nursing home, Reed *et al.* (1998) highlight the importance of 'place' for each individual seeking admission to a care home. In other words, the location of the home should allow residents to share memories of their community with other residents and maintain links with family and friends. Most family caregivers are obviously in an ideal position to assist with these decisions.

The limited opportunities to explore a number of homes also frequently results in the initial contact between carers and the chosen home being somewhat perfunctory. This, however, is a crucial phase in the transition (McDerment *et al.* 1997) in which relationships and expectations are established. The early development of trust between carers and prospective homes is essential to fostering positive future interactions (Relatives Association 1994, McAuley *et al.* 1997) and therefore visits to potential homes are beneficial not only to carers but also in assisting staff to obtain important information about care needs (Ehrenfeld *et al.* 1997). Unfortunately homes often receive inadequate information, not only because of the limited contact with carers, but also due to poor transfer of information from hospitals (Nolan *et al.* 1994a, Audit Commission 1997, Reed and Morgan 1998).

Older people and their relatives will adapt to life in a nursing home in a variety of ways and support should be tailored accordingly (Savishinsky 1991, Patterson 1995, Reed and Payton 1996). Reed and Payton (1996) argue that care staff need to recognise the hard work that older people perform when they move into a care

home in relation to fitting in with existing conventions and rules, what they term 'constructing familiarity and managing the self'. It is likely that family caregivers may have to undertake similar activities in order to 'fit in' with the culture of the care home. The period of transition is likely to be made easier if the exact purpose and nature of the admission has been clearly discussed and agreed with the older person and their family. Increasingly, admission to a care home may not necessarily be a permanent decision and the role of nursing homes in providing respite care and rehabilitation is gradually expanding (Blair 1995, Baltes *et al.* 1994, Salgado 1995). However, for most new admissions, the care home will provide their final abode. It is therefore important to understand the experience of life in a home as relatives' desire to ensure the best care for the cared-for person is an important feature of the caregiving relationship (Bowers 1988, Nolan *et al.* 1996b).

Experiences of life in a care home

A number of research studies have explored the experience of living in a care home from the older person's perspective. An appreciation of this literature is essential in order to suggest appropriate roles for family caregivers following admission. A range of experiences are described but it is clear that, at its worse, life in a care home is characterised by a sense of powerlessness, vulnerability and loss of meaning (Nystrom and Segesten 1994, Casey and Holmes 1995, Liukonnen 1995). Numerous studies and anecdotal accounts over several decades have described how older people can be stripped of their identity on admission to a care home (Robb 1967, Laird, 1982, Nystrom and Andersson-Segesten 1990). Furthermore, such experiences have been confirmed by the findings of a series of observational studies reporting low levels of staff-resident interaction and minimal involvement in social activities in a range of settings providing continuing care (Armstrong-Esther *et al.* 1994, Nolan *et al.* 1995, Gilloran *et al.* 1994). Much of this evidence suggests that care home staff prioritise residents' needs for physical care over their needs for social and emotional support. In interviews with 31 residents of two nursing homes in Finland for example, Liukonnen (1995) found that nursing staff were clearly preoccupied with daily

activities, whereas the lives of elderly residents received less attention. There was a widespread feeling among residents that staff members were always pressed for time and did not want to talk with them. Yet, what these residents wanted most was someone in their daily lives who would *'share with them their joys and sorrows and reminisce with them'*. Liukkonen 1995 p367). These findings suggest that residents particularly value the interpersonal aspects of care.

Wilde *et al.* (1995) report a study of older peoples' perceptions of quality in four different care environments, including nursing homes. In structured interviews with 428 residents, they found high ratings for items relating to medical/technical competence of caregivers and physical-technical conditions of the care environment, but much lower ratings for interpersonal dimensions of care. A smaller qualitative study of 46 residents of one nursing home in the United States found that the quality of interpersonal relationships with staff members was the most important aspect of quality of care for the residents (Grau *et al.* 1995). In combination, the findings of these studies suggest that while most older people living in care homes feel that their needs for physical care are largely met, care aimed at maintaining their psychological well-being is more elusive. Furthermore, there is evidence of a gap in understanding between the older residents of care homes and the staff caring for them in terms of perceptions of need. A recurrent theme within the literature is that professional caregivers identify different priorities for frail older people in their care than older people identify for themselves (Bartlett 1993, Bliesmer and Earle 1993, Bowsler 1994, Jacobson and Winograd 1994, Oleson *et al.* 1994).

Vulnerability and powerlessness The vulnerability which older people feel as a result of their dependence on nursing home staff has been vividly described in many first hand-accounts (Laird 1982, Nystrom and Segesten 1994, Reed and Payton 1996). Care staff are in a position to act as gatekeepers to essential care (Herzberg 1993), medical care (Gillick *et al.* 1996), pain control (Ferrell 1995) and opportunities for social interaction (Gilloran *et al.* 1994, Nolan *et al.* 1995). The regular exclusion of older people and their families from discussions about their care and progress (Norburn 1995) is a further example of the ways in which older

people living in nursing homes can be disempowered. This is disturbing in light of evidence to suggest that involvement in decision-making has positive benefits for the residents of nursing homes, with several studies demonstrating a relationship between the maintenance of personal control and resident outcomes such as psychological well-being and satisfaction with care (Beery 1993, Chen and Snyder 1996, Warner 1997). Chen and Snyder for example found that residents' perception of personal control explained 54% of the variance in satisfaction with care (Chen and Snyder 1996). Providing opportunities for residents to make even small choices and decisions regarding their daily lives can increase their perception of autonomy and control, both of which are often severely curtailed in an institutional environment. (Goodwinjohansson 1996).

Loss of personal identity Identity is linked closely with the notion of self-esteem, which has been described as one of the main ingredients of quality of life in old age:

'Positive self-esteem is a sense of integrity and identity, founded on connections to the person one has been, memories, roles, unique qualities, relations, belongings and home.'

(Nystrom and Andersson-Segesten 1990 p 57)

Perhaps more than in any other care environment it is essential to base the care of older people living in nursing homes in the context of their whole life development. The importance of building plans of care based on an older person's biography is evident from the above definition of the importance of self identity. However, biographical detail within nursing assessment and documentation is often limited (Brocklehurst and Dickinson 1996). There is also evidence that family caregivers are frequently not involved in the care planning process (Norburn *et al.* 1995, McDerment *et al.* 1997).

Cookman (1996) describes how things, places, animals and ideas can be sources of security, belonging and self-identity for older people and argues that care staff need to see the environment of the care home as a supportive resource, for

example using objects and visitors to induce reminiscence and to remind staff of the older person's background and interests. Family caregivers have an obvious role to play here.

The importance of relationships The importance of maintaining family relationships following the move to a nursing home, both for the older person and their family members, has been clearly demonstrated (Bogo 1987, Daley 1993, Gladstone 1995, Lawton *et al.* 1995b, Ross *et al.* 1997). For example, in a novel study, essays were gathered from fifty-three elderly nursing home residents in which they were asked to describe the strongest meaning in their lives (DePaola and Ebersole 1995). Residents most often reported the category of family relationships as central, followed by pleasure (enjoyment of each day) and then health. Using a more structured approach Lawton *et al.* (1995b) found that family-related events were frequently associated with positive feelings among 79 nursing home residents.

Few studies have considered the effects on a relationship of a spouse or partner moving into a care home. In particular, the need for intimacy and a continuing sexual relationship have received little attention (Kaplan 1996). On the basis of in-depth interviews with three community-dwelling wives, Kaplan and Ade-Ridder (1991) describe the difficulty of maintaining intimacy within a public setting. For community dwelling spouses, adjusting to living alone, dealing with loneliness and a lack of companionship also provide major challenges (Ade-Ridder and Kaplan 1993). Other commentators have described how the grieving process is 'elongated' because the spouse is not free to resume his or her life (Sommers and Shields 1987). In the UK, a study by Beyleveld (1997) involved interviews with seven community dwelling spouses. Participants indicated that they were given no opportunity or choice to embark upon, or continue a spouse-carer role. Lack of privacy was a particularly important factor limiting spouses' ability to continue their relationship in the way they would like.

Residents also benefit from opportunities to build relationships with other residents and their families (Wilkin and Hughes 1987, Powers 1992, Patterson

1995, Reed and Payton 1996). Kovach and Robinson for example interviewed 50 elderly residents of six nursing homes (Kovach and Robinson 1996) and found a relationship between room-mate rapport and life satisfaction for those who were able to converse. Doyle (1995) also found a significant relationship between absence of close friends among other residents and depressive symptoms. Yet staff in care homes frequently fail to recognise the significance of the relationships which residents have with each other (Reed and Roskell Payton 1996). The social value of meal-times for instance is often neglected (Liukkonen 1995, Sidenvall *et al.* 1996).

The importance of dining with relatives as a social event has also been demonstrated in the literature (Schneewind 1990, Kayser Jones 1996, Naleppa 1996). Using case studies of four residents in one US nursing home for example, Schneewind (1990) identified the value of a family meal shortly after admission as a familiar ritual which may ease adjustment. Opportunities for shared activities help to create a sense of community, provide a focus for visiting and can improve quality of life and cognitive functioning (Allen and Turner 1991, Turner 1993). Despite this, there is very little in the literature concerning the role of designated activity co-ordinators within care homes although a survey of 200 Australian nursing homes found a positive relationship between the presence of an activities co-ordinator and the range of experiences enjoyed by residents (Pearson *et al.* 1992).

The difficulties that many frail older people living in care homes experience in maintaining and creating relationships can be compounded by communication problems. Numerous studies for example have found high levels of hearing loss among residents of nursing homes (Mahoney 1992, Stumer *et al.* 1996, Tolson and McIntosh 1997). On the basis of a review of the mainly US literature in this field, Lubinski (1995) suggests there is likely to be little communicative interaction in nursing homes and that communication, when it does occur is likely to be impoverished. This is attributed to a range of factors including:

- ◆ the paucity of communication services to meet the needs of residents;

- ◆ barriers to the uptake of services including cognitive impairment of residents;
- ◆ physical health problems and the lack of access to on-site testing coupled with the expense of travel to off site assessment and treatment.

(Lubinski 1995)

The potential resource implications for overcoming these barriers suggest that initiatives within the home are likely to be more successful in improving residents' ability to communicate. A number of evaluation studies have demonstrated improvements in communication following structured intervention programmes, some of which involve family members (Buckwalter *et al.* 1991, Jordan *et al.* 1993). Jordan *et al.* (1993) found positive gains in communication skills and self-management of communicative impairment for a number of residents following intervention programmes implemented by volunteers. Similarly, Buckwalter *et al.* (1991) found that a family-centred intervention aimed at improving residents' communicative ability, while having a modest impact on residents' speech, significantly increased family members' satisfaction with many aspects of the residents' care. Modifying the 'listening environment' through strategies such as rescheduling cleaning activities have also been shown to be effective in improving communicative ability (Tolson and McIntosh 1997).

In summary, the literature describing experiences of living in a nursing home confirms the potential for isolation within an alien environment if residents are not encouraged and enabled to maintain important relationships and create new ones. Similarly, the frailty of many older people at the time of admission renders them vulnerable to the loss of personal autonomy and identity. The potential benefits for all concerned of creating a sense of community within care homes, nurturing relationships and creating links with the outside world seems clear. However, the literature to date does little to expel the negative images of care homes outlined previously. Given the natural desire of carers to be the 'arbiters' of the care their

relative receives, (Twigg and Atkin 1994), this raises important questions about the role of family caregivers in the life of the home.

Uncertainties about the role of family caregivers following placement

There is relatively little within the literature linking the experiences of life in a care home outlined in the previous section with a potential role for family caregivers. This is perhaps surprising given that the difficulties family caregivers experience in replacing caregiving, and the sense of role loss at this time, have been described by a range of commentators (Robinson and Thorne 1984, Ritchie and Ledesért 1992, Gladstone 1995, Aneshensel *et al.* 1995, Dellasega and Mastrian 1995). Furthermore, there is evidence that care staff frequently fail to recognise and draw upon the expertise of family caregivers in planning and implementing care for the older person (Naleppa 1996), in spite of evidence demonstrating the benefits for all concerned of involving family members (Buckwalter 1991, McDerment *et al.* 1997). In a Scandinavian study of seven relatives' experiences, Hertzberg and Ekman for example highlight the tendency for staff to stereotype families and ignore their unique caregiving histories (Hertzberg and Ekman 1996).

Dellasega and Mastrian (1995) suggest that role redefinition is a crucial task for carers following placement of a relative in care. Kellett (1996) provides further illumination in an Australian study of the experiences of fourteen relatives of care home residents. She describes four themes that encapsulate the way families seek to maintain a sense of attachment to their relative. These are:

- ◆ engaged involvement - to reduce role loss and create new ways of caring;
- ◆ worth - ensuring that their specialised knowledge of the older person is used as a basis for planning quality care;

- ◆ concern - about how to negotiate boundaries between themselves and staff in the home;
- ◆ continuity - how to remain involved and continue to share a fruitful relationship with the older person.

Simultaneously, carers' sense of ownership of expert knowledge in relation to the older person and their desire to convey this to staff as a basis for care planning is increasingly apparent (Robinson and Thorne 1984, Bloomfield 1986, Bowers 1988, Ross *et al.* 1993, Pillemer *et al.* 1998), with perhaps the most complete account of differing types of knowledge and care being provided by Bowers (1988). On the basis of semi-structured interviews with mainly female adult children, Bowers (1987) initially identified five distinct but overlapping categories of family caregiving: anticipatory, supervisory, preventive, instrumental and protective. A subsequent study explored the relevance of these categories to family caregiving within a nursing home setting and identified an additional category of preservative care (Bowers 1988). Four types of preservative care were identified:

- ◆ maintaining family connectedness;
- ◆ maintaining their relative's dignity;
- ◆ maintaining their relatives' hopes;
- ◆ helping their relative maintain control of the environment.

(Bowers 1988)

Maintaining connectedness was seen as largely the family's responsibility. Other types of preservative care required collaboration between staff and family members and involved teaching the staff how to deliver high quality care, picking

up where the staff failed and providing direct care. Bowers suggests that carers see one of their main roles as being to monitor the quality of care that their relative receives. This requires achieving a balance between the technical aspects of care, largely seen as the province of staff, and the personal, biographical knowledge of the carer. Family caregivers expect staff actively to seek such knowledge, for example, regarding the older person's like and dislikes, hopes and aspirations, and to incorporate it into their care planning. It is this blending of technical and biographical care that is the primary aim of 'preservative' care, which is intended to maintain the dignity and self-esteem of the older person (Bowers 1988).

The notion that family caregivers monitor the quality of care received from formal services prior to entry to care has been described a number of times (Twiggy and Atkin 1994, Nolan *et al.* 1996a) and it is quite apparent that this is a key role following admission, with concern over quality of care being one of the main anxieties reported (Woods and MacMillan 1992, Ritchie and Ledesért 1992, Gladstone 1995, Ehrenfeld *et al.* 1997). Bowers (1988) identifies three strategies used by family members to evaluate care: direct observation, indirect observation (asking the resident) and assessing outcomes (for example - whether the older person is depressed or agitated). Based on their assessments, Bowers (1988) contends that families may also feel the need to 'teach' staff how to care. Methods for teaching staff include: telling stories about the older person to reveal their identity to staff, teaching the right way through demonstration and role modelling, and sharing with the staff the outcomes of inadequate care (although this was often approached with caution). Relatives in Bower's study identified a lack of communication between staff and felt that this contributed to the lack of preservative care. The expectations of many family members were not met suggesting that their initial orientation to the nursing home environment was inadequate.

It is apparent from this brief discussion that most family caregivers perceive a clear role for themselves in supporting their relative following admission to a nursing home. The extent to which they are supported and enabled to fulfill this role will now be considered.

Current practice in relation to supporting and involving relatives within care homes

Given the emotional sequelae of nursing home entry discussed earlier, attention to the needs of family caregivers following placement is an area of practice that merits attention. Unfortunately the literature would suggest that interactions between staff and carers are far from ideal, and indeed are often a source of considerable conflict. Historically relatives who wish to play a significant role in care have tended to be seen as interfering (Robinson and Thorne 1984, Darbyshire 1987) and as a result, adversarial and competitive relationships can rapidly develop (Buckwalter and Hall 1987, Ehrenfeld *et al.* 1997, Pillemer *et al.* 1998). A consequence is that tensions with staff are another frequent concern expressed by relatives (Pratt *et al.* 1987, Woods and MacMillan 1992, Gladstone 1995, McDerment *et al.* 1997). While the creation of positive relationships between staff and relatives is a key factor in reducing potential conflict (McAuley *et al.* 1997, McDerment *et al.* 1997) this aspect of care is rarely given priority. Wagner (1997) for example suggests that staff/relative relationships are 'overlooked, almost suppressed'.

A recent major study in the UK suggests that a considerable proportion of relatives are dissatisfied with their relationships with care home staff. McDerment *et al.* (1997) explored perceptions of relationships through a series of focus group interviews with residents, relatives and staff in 100 nursing homes in the UK. The authors highlight a general lack of awareness of the significance of relatives and friends among staff, to the point that these groups seem to be 'occupying separate planets, each with their own solar systems'. As a consequence there was little understanding of family dynamics or the complex emotions carers experience, nor was there evidence of an open climate and a positive attitude towards relatives (McDerment *et al.* 1997). Despite such obvious deficits no coherent policy for dealing with relatives emerged from the study and attention was rarely turned to this aspect of the home environment until something went wrong. McDerment *et al.* (1997) argue that participation of relatives in the life of a home is different

from simply visiting and that it requires a proactive and planned approach based on:

- ◆ recognition of the potentially competitive nature of the relationship between staff and visitors;
- ◆ accessibility of staff;
- ◆ mutual clarification and understanding of roles and expectations;
- ◆ effective two way communication.

(McDerment *et al.* 1997)

An important finding of the study was the lack of congruence between the expectations of staff and relatives. Managers for example often saw the relationship with relatives as exclusively 'theirs'. They were fronting the home and managing external relationships. Care workers were confused about the degree of interest they should show in relatives without appearing to intrude. Staff usually saw the contact between residents and their relatives as private so they avoided any active involvement that might be seen as contrary to good practice. On the other hand, relatives requested help and encouragement in visiting, expressing a need for emotional and practical support from the home. These findings highlight the importance of regular communication between all stakeholders if relatives' needs are to be more fully met.

Care at the end of life provides a further indication of the extent to which care home staff perceive that they have a role in supporting family members. Regular confrontation with the processes of death and dying is a feature of nursing home life and this is likely to be stressful for staff, residents and relatives (Savishinsky 1991, Abrams *et al.* 1992, Robbins *et al.* 1992, Moss *et al.* 1993, Aday and Shahan 1995). Commemorating death and carrying out rituals which remind and

demonstrate to others that a death has occurred is an important way of sensitising people to loss and also challenges the denial of death (Costello 1996). However, the literature revealed few studies which have considered the support needed by relatives following the death of a resident. One North American study (Murphy *et al.* 1997) considered the bereavement services available for families of older people with Alzheimer's disease living in long-term care facilities. A survey of 121 nursing homes revealed that 98% of homes neither arranged for staff to visit, made phone calls or provided written information to family members in the period following a resident's death. This isolated study suggests a need to evaluate current practice in this area.

A number of authors have argued that nurses are in an ideal position to facilitate more positive interactions between staff and family carers (McLeod and Schwartz 1992, Ross *et al.* 1993, 1997) with the suggestion being that attention to the needs of families should be viewed as a legitimate and integral part of care (Pratt *et al.* 1987, Aneshensel *et al.* 1995, Gladstone 1995). In order to maximise opportunities it is advocated that contact should be initiated prior to admission (Buckwalter and Hall 1987, Ehrenfeld *et al.* 1997) with obtaining the views of families forming a core component of the admission process (Ross *et al.* 1993). In this context the actual move into the home is a key phase in the adjustment process (McDerment *et al.* 1997). Several dimensions of the interface between home and family have been identified as potentially fruitful areas for further intervention, including:

- ◆ helping carers to create a positive perception of the admission, acknowledging their need to both receive and provide help, dealing with emotional reactions and being alert for signs of depression or lowered mood among carers (Pratt *et al.* 1987, Gladstone 1995, Ross *et al.* 1993, 1997, McDerment *et al.* 1997);
- ◆ creating a welcoming environment, which encourages and supports visiting, working with carers to maximise their involvement and facilitate a sense of purpose (Pratt *et al.* 1987, Ritchie and Ledesért 1992, Anderson *et al.* 1992, Ross *et al.* 1993, 1997, McDerment *et al.* 1997);

- ◆ recognising and clarifying roles and responsibilities for both groups (Pratt *et al.* 1987, Buckwalter and Hall 1987, Ross *et al.* 1993, McDerment *et al.* 1997);
- ◆ valuing and accessing carers' knowledge and expertise and utilising this as an important component of planning care (Pratt *et al.* 1987, McLeod and Schwartz 1992, Buckwalter and Hall 1987, Ross *et al.* 1993, 1997, Anderson *et al.* 1992, McDerment *et al.* 1997).

Although this list seems logical and provides a clear indication of the areas to which attention can be turned, it also places considerable responsibility on the staff. Creating equitable relationships is a two-way process and there is growing recognition that individual members of staff and the organisation as a whole have needs which must also be acknowledged. This is often particularly relevant to care staff who provide significant amounts of direct support but can feel that their contribution is not fully recognised. Heiselman and Noelker (1991) for instance, in a study of nursing assistants' perceptions of the respect they receive from relatives, found that many did not feel valued and were frequently accused of delivering poor care by relatives. Staff in care homes would like to be treated politely, to be given respect for their competence, and to have the relationships they have established with residents acknowledged. As McDerment *et al.* (1997) point out, staff are often working under considerable resource constraints and there is a need to help relatives appreciate what is attainable and realistic within the limitations imposed by care in a group environment. Interventions which therefore focus only on the perceptions of relatives are unlikely to be optimally effective (Pillemer *et al.* 1998).

Nolan and Grant (1993) highlight the importance of reciprocity within caregiving relationships for staff in long-stay settings, particularly in reducing occupational burnout. However, systems for organising care, such as named nursing, and key worker systems, which could encourage and support relationships between staff, residents and family caregivers, are often resisted. For example, an audit of care plans for 298 residents in 17 care homes in the UK found that less than half of the residents had a key worker (Brocklehurst and Dickinson 1996). This is in spite of

evidence to suggest that consistent staff allocation results in greater resident satisfaction with care (Patchner and Patchner 1993, Teresi *et al.* 1993).

A number of studies have described efforts to improve and enhance staff/relatives relationships and involvement (Drysdale *et al.* 1993, Campbell and Linc 1996, Pillemer *et al.* 1998). They have ranged from specific interventions aimed, for example, at helping relatives communicate more effectively with residents who have speech deficits (Shulman and Mandel 1988), or to interact more effectively with residents with cognitive impairment (Hansen *et al.* 1988), to programmes intended to create greater cooperation between staff and families at a more generic level. Anderson *et al.* (1992) for instance designed a simple experiment conducted in two groups of six homes in which one group (experimental) introduced a system whereby staff actively sought biographical information from family carers and used this as a basis for care planning. Relatives were also encouraged to participate in setting joint goals. In the control group normal practice was maintained. Evaluation suggested a number of benefits for the experimental group including simpler and more attainable care goals, greater family involvement, reduced use of medication and more individualised care. Benefits also emerged for staff who reported less burnout and fatigue, improved attitudes towards residents and relatives and increased job satisfaction.

In another example of a partnership approach between staff and relatives Pillemer *et al.* (1998) outlined a comprehensive training approach. This was based on parallel, but initially separate, workshops for staff and relatives where a number of issues were shared. The evaluation suggested benefits in 3 broad areas:

- ◆ new insights into the needs of relatives/staff;
- ◆ changes in behaviour towards relatives/staff;

- ◆ observed changes in behaviour by relatives/staff.

(Pillemer *et al.* 1998)

Although the authors were positive about their findings they sounded a note of caution, highlighting the organisational commitment that is needed so that staff can be released from their duties to attend the workshops. Furthermore, as new relatives arrive and staff turnover results in differing staff groups there is a need to provide the programme on a rolling basis. This has obvious implications in an already resource constrained environment. A further area of concern is the need for staff to consider ways to support relatives during visits, particularly where the resident is cognitively impaired and conversation is difficult (Hertzberg and Ekman 1996, Ross *et al.* 1997).

As Aneshensel *et al.* (1995) point out, it is important to recognise that not all families experience difficulties with nursing home staff. Looman *et al.* (1997) for example explored family members (n = 133) positive perceptions of the care provided by nursing assistants to residents with dementia and identified four positive themes:

- ◆ appreciation of how difficult it is to care for people with dementia and an understanding of the constraints imposed by understaffing, heavy workloads, and low wages;
- ◆ recognition of care provided by nursing assistants that exceeds expectations;
- ◆ positive expressions between nursing assistants, residents and residents' family members;

- ◆ identification of a kin-like relationship between residents and nursing assistants.

(Looman *et al.* 1997)

However, such experiences were the exception within the literature reviewed and there is a clear imperative to identify ways in which staff and relatives can more effectively work together. Concerted efforts to address many of the issues identified in the literature have the potential not only to create more equitable relationships but also to influence the longer term adjustment and health of family carers (Aneshensel *et al.* 1995, Gladstone 1995, Ross *et al.* 1997).

Summary

This review has explored selected items of the literature on experiences of admission to a nursing home with the intention of identifying key themes and issues to inform the current study. On the basis of this preliminary review, it is apparent that there is considerable scope for improvement in health and social care practice which will enhance family caregivers' experiences of helping a relative to move into a care home. In particular, there is evidence to suggest that family caregivers need information and support with:

- ◆ the initial process of deciding that alternative care arrangements are needed;
- ◆ subsequent decisions about which home to select;
- ◆ establishing and sustaining longer-term relationships with staff in the home;
- ◆ maintaining their relationship with their relative in a way which continues to have benefits for all concerned.

The temporal nature of family caregiving implies that the needs of family caregivers will change at key points within the caregiving career and that

supportive interventions need to be tailored to the particular stage reached. However, the literature suggests that family caregivers' needs are poorly addressed at all stages of the move to a care home and beyond, particularly with respect to information upon which to base an informed choice and preparation for the emotional consequences of the placement process. Family members experience loss, guilt and grief, and report that these emotions continue throughout the time that their older member is in the nursing home. There are however few published reports of practice interventions to help relatives to prepare for the move.

A number of factors have been associated with helping relatives to come to terms with nursing home entry, including a perception of having control over the situation and the acceptability of the nursing home. These factors also point to the importance of providing adequate information to allow relatives to make informed choices.

Experiences of life within a care home are varied but at worst result in disempowerment and loss of control for both older people and family caregivers. Most family caregivers wish to maintain active involvement in the life and care of their relative; however, there appears to be little willingness on the part of caregiving staff to actively negotiate the nature and extent of this involvement. Admission assessment normally focuses entirely upon the needs of the new resident to the extent that the difficulties that relatives experience are often ignored. Furthermore, care staff seem to be largely unaware of their potential role in supporting family caregivers in adjusting to the transition and in enabling them to develop a modified caregiving role.

More generally there is some evidence that involvement with nursing home residents by relatives can have positive effects for both relatives and residents. Additional research is needed to identify the types of involvement that result in positive outcomes and the best means of achieving this. However, there are some signs that the involvement of relatives is not always welcomed by staff.

The literature attests to the importance of relationships within care homes and a sense of 'community' in achieving positive experiences for older people and their family caregivers. In particular, the following sets of relationships are significant:

- ◆ relationships between relatives and the older person;
- ◆ relationships between relatives and staff;
- ◆ relationships between the older person and staff;
- ◆ relationships between the older person and other residents.

It seems likely that the nature of these relationships is an important factor influencing perceptions of care.

The main intention of this review was to identify a set of issues which would inform data collection and analysis: in Morse's words 'to recognise research leads without being led' (Morse 1994 p27). The issues described here helped to provide some direction for the study. However, existing work did not dictate or dominate data collection and analysis. Rather the literature was used to raise my awareness of the context for data collection and suggest broad topics for exploration with research participants.

Furthermore, it seemed important at this stage to reconsider the original objectives for the research in the light of these issues. The planned focus on the experiences of relatives (rather than older people) remained appropriate given the limited volume of literature exploring nursing home admission from this perspective, particularly within the UK. In view of the tensions surrounding decisions about long-term care options, and the suggestion that experiences of admission to care homes are predominantly negative, it seemed appropriate to explore and compare experiences in order to begin to suggest appropriate care practices and interventions at this time. The significance of relationships in shaping care

experiences suggested that these relationships should form an important focus when exploring current practice within nursing homes. Finally, indications that current practice is failing to meet the needs of family caregivers at the stage of relinquishing the main caregiving role and beyond, confirmed the need to generate information and debate to develop practice in this area. The literature therefore, while suggesting a number of nuances and emphases, confirmed that the original objectives for the research were timely and appropriate (see Chapter 1 page 10).

In the following chapter I describe the methodology for the study and attempt to illustrate how these objectives were pursued.

CHAPTER 3. METHODOLOGY

Introduction

In this chapter I describe the approach to data collection and analysis used within the study. I begin with a consideration of the assumptions underpinning the general constructivist approach which guided the research, and then describe the broad research strategy and the methods used at each stage of the study. Ethical issues are considered in relation to each data collection method and frameworks for the analysis of data are outlined. Further reflections on the methodology are included within chapter 6.

Being guided towards a qualitative approach

Given the diverse range of issues highlighted within the literature review, and the nature of the questions guiding the study, a qualitative approach seemed the most appropriate. However, qualitative research is an increasingly complex area and although the various approaches share common factors it is still necessary to select a particular strategy to address the questions of interest. This section briefly considers the rationale for the decisions made with regard to the present study. Denzin and Lincoln (1994) have provided the following generic definition of qualitative research:

'Qualitative research is multi-method in focus, involving an interpretive, naturalistic approach to its subject matter. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them. Qualitative research involves the studied use and collection of a variety of empirical materials - case study, personal experience, introspective, life story, interview, observational, historical, interactional and visual texts – that describe routine and problematic moments and meaning in individual's lives. Accordingly, qualitative researchers deploy a

wide range of interconnected methods, hoping always to get a better fix on the subject matter at hand. '

(Denzin and Lincoln 1994, p2)

They go on to suggest that qualitative research privileges no single methodology, nor does it have a distinct set of methods. Rather, the emphasis is on exploring:

- ◆ processes and meanings;
- ◆ the socially constructed nature of reality;
- ◆ the intimate relationship between the researcher and what is studied;
- ◆ the situational constraints that shape inquiry.

Qualitative research therefore primarily seeks to answer questions about how social experience is created and given meaning. The focus is usually exploratory and descriptive and the intention is not the generalisation of findings, but rather a deeper understanding of experience from the perspective of participants selected for study (Maykut and Morehouse 1994). Consequently, qualitative research designs are particularly appropriate when relatively little is known about the phenomenon of interest (Brink and Woods 1988) and the aim is to understand how phenomena are experienced. Hence a qualitative approach was entirely consistent with my original objectives for the study. However, given the broad canvas that now constitutes qualitative research, important decisions remained to be made about the appropriate approach to take.

Finding a perspective

Within the broad field of qualitative research, a range of perspectives and strategies are described, often differentiated by quite fine distinctions (Schwandt 1994). Miller (1997) suggests that qualitative methodologies can be seen as positions

taken by researchers for observing settings and relationships within those settings. As a consequence, both the descriptions of social reality that might be constructed by qualitative researchers and the possible interpretations of these descriptions will vary depending on the observational and analytical positions adopted. These positions, or viewpoints, in turn are likely to be determined by the paradigm within which the study is located.

Guba and Lincoln (1994) describe a paradigm as a basic belief system or world view that guides the investigator, not only in choices of method but in ontologically and epistemologically fundamental ways. Research paradigms are generally classified on the basis of assumptions or beliefs in relation to three philosophical questions:

- ◆ The ontological question: what is the nature of reality?
- ◆ The epistemological question: what is the relationship between the inquirer and the known?
- ◆ The methodological question: how can we gain knowledge of the world?

Melia (1997) proposes a pragmatic approach to qualitative methods which takes account of philosophical and epistemological debates but does not become so pre-occupied with them that any form of research can be vetoed on some ground or another. A further constraint is highlighted by Miller (1997) who recognises that qualitative researchers are not always free to choose their methods: rather methodological decisions are likely to be influenced by organisational constraints and practical considerations. Some of the pragmatic considerations which informed the present study have already been alluded to (see Chapter 1), but it also seemed important that a decision about which approach might be most relevant was informed by the aims of the study.

The variety within qualitative methodology is potentially confusing and it seems that some of the debates, as with theory, can be ‘splitting hairs’ (Melia 1997). From the definition of Denzin and Lincoln (1994) cited earlier it seemed that almost any qualitative method would meet my desire to reflect the ‘experiences’ of people. However, I also felt that it was essential to select an approach that provided new insights (that is I wished to add to theory) but did so in such a way that any resultant ‘knowledge’ was accessible and seen as relevant by the participants themselves. Therefore, whilst I hoped that the study would be useful in informing professional practice, I also wanted it to empower older people and carers. I read extensively around a variety of qualitative approaches, but the more I read, the more I became attracted to a constructivist model. This, as will be highlighted below, addressed the questions about ontology, epistemology and methodology in a way that was entirely consistent with the aims of the study. Moreover, constructivism is promoted within the field of gerontology as a way of capturing ‘everyday life’ in older age that reflects the perspectives of older people using their own terms and frames of understanding (see for example Gubrium and Sanker 1994). Equally influential in helping me reach this important decision was a text by Rodwell (1998) which, from a practitioner’s (social work) perspective highlighted the link between constructivist research and practice.

The constructivist approach

Having, as described above, considered a raft of qualitative methodologies, a constructivist approach seemed particularly relevant as it:

- ◆ has a relativist ontology that accepts that there are multiple realities. This was important given my desire to focus on a range of experiences within different care contexts;
- ◆ has a subjective epistemology in which the knower and the researcher jointly create understanding;

- ◆ has a naturalistic methodology involving a dialectic between the investigator and participants which often produce a grounded theory.

(Rodwell 1998)

Schwandt (1994) suggests that constructivism and interpretivism are general descriptions of a loosely coupled family of methodological and philosophical persuasions that share the general goal of understanding the complex world of lived experience from the point of view of those who live it (p118). He further comments that constructivism and interpretivism are best regarded as ‘sensitising concepts’ which steer researchers in a general direction, with the particular meanings and methods being shaped by the intent of the researcher. As noted above, my intention within this study was not only to produce new insights which might help me understand the experience of placing a relative in a nursing home, but also generate to knowledge which would inform practice and change.

In developing these arguments further Rodwell (1998) contends that constructivism provides a different way of ‘rigorous knowing’ which offers the promise of meaningful knowledge to guide practice.

‘Constructivist inquiry provides a mechanism for providing rigorous and relevant information for social work interventions’.

(Rodwell 1998 p3).

In this context the primary purpose of a constructivist inquiry is to produce new insights that enhance an individual’s ability to make informed choices that can lead to effective change. Since my main intention within the research was to inform nursing interventions and empower older people and carers, Rodwell’s interpretation of constructivism seemed particularly appropriate and provided an important principle and framework guiding the research process.

Certain assumptions underpin Rodwell's interpretation of the constructivist approach. These are as follows.

- ◆ Reality is multiple, constructed and holistic. An emic perspective facilitates an understanding of shared cognitive maps that allow individuals to impose meaning on their individual experiences. Through the use of common referent terms, realities are constructed that are hopefully consensual but seem reasonable and make sense to participants. It is important to identify all stakeholders.
- ◆ The inquirer-participant relationship is interactive and all participants are changed by the process. The quality of the human instrument is therefore essential to data collection.
- ◆ Generalisation is not strictly possible and all findings are 'tentative'. The researcher produces a final report with sufficient richness that an informed reader can make the determination of relevance for another context.
- ◆ Causality is not assumed as there are multiple realities but it may be possible to identify patterns of meaning within a given context.
- ◆ All inquiry is value based and an appreciation of context is central to understandings and meanings.

Rodwell proposes that a constructivist approach can be adapted to suit most types of research questions providing that the aims of the study are consistent with the above assumptions. The intention of a constructivist inquiry is to produce an enhanced understanding which, although not deterministic and predictive, provides a guide for action by sensitising individuals or groups to the likely consequence of a certain combination of factors. As Rodwell (1998) notes:

'Concepts and their meanings in relationship are the cornerstones of a socially constructed reality and of constructivist inquiry'

(Rodwell 1998 p118)

In other words the aim is simply not to identify isolated concepts, but rather to focus on the relationships between them and their potential interactions and effects within a given context.

Having decided upon a general approach it was then necessary to consider how this might be operationalised within the current study.

Research Design

Lincoln and Guba (1985) suggest that the research design within a constructivist inquiry involves:

'Planning for certain broad contingencies without however, indicating exactly what will be done in relation to each.'

(Lincoln and Guba 1985, p 226)

Thus, as noted by others, it is inappropriate to determine the exact process of a constructivist inquiry in advance (Rodwell 1998). As advocated by Erlandson *et al.* (1993), the skill of constructivist inquiry is to handle complexity with flexibility with the notion of an emergent research design being central to constructivist inquiry. This involves an interactive and iterative process of data collection and analysis. A constructivist study does not therefore proceed in a neat linear fashion; rather there is considerable overlap between the design, data collection and analysis phases.

The constructivist perspective suggests that data will be gathered from a variety of sources and in a variety of ways:

'Respondents are asked questions but they are also encouraged to engage with the researcher in less structured conversations so that their hidden assumptions and constructions begin to surface. They are observed in their daily activity so that the researcher can begin to see the operational meaning of what they have said. Further insight into their constructed realities can be gained from documents that provide a historical context for interpreting their words and activities. Data from all these sources are brought together and systematically analysed in a process that proceeds parallel to data collection.'

(Erlandson *et al.* 1993, p 81)

The process of inquiry for the researcher becomes one of developing and verifying shared constructions that will enable the meaningful expansion of knowledge (Erlandson *et al.* 1993).

Rodwell (1998) provides a more detailed account which identifies the following methodological requirements and assertions of a constructivist inquiry:

- ◆ the research is conducted in a natural setting, because reality cannot be understood in isolation from the context that gives it meaning;
- ◆ primary data gathering is performed using the human instrument (i.e. the researcher) as this is the only instrument capable of grasping meaning in interaction;
- ◆ tacit knowledge is required to understand nuances and should be used in addition to propositional knowledge to communicate meaning;
- ◆ qualitative methods are generally preferred as they are more adaptable and capable of dealing with multiple, and potentially disparate, realities;

- ◆ the research focus determines the boundaries of the study - in other words the real question and who knows the answer(s) are based on an emergent focus that allows the multiple realities to shape and define the research;
- ◆ purposive sampling increases the scope and range of data collection in order to look for multiple realities;
- ◆ inductive data analysis subsumes raw units of information into categories to make sense of the context of the investigation;
- ◆ grounded theory emerges from the inquiry because an *a priori* theory would not be able to encompass the specifics of the multiple realities of a particular context;
- ◆ the research design emerges as the study progresses, rather than being developed in advance of data collection. This is because no inquirer can fully appreciate the possible range of realities which will inhabit a particular context;
- ◆ outcomes, in terms of meanings, interpretations and final products are negotiated with participants since they retain ownership of the data;
- ◆ findings are generally reported in case study format as this better captures multiple realities and makes the results more accessible to participants;
- ◆ the aim is to produce contextual interpretations rather than law-like generalisations;
- ◆ while findings may have relevance for other contexts, any application must be tentative and negotiated;

- ◆ research rigour is determined in terms of criteria for trustworthiness and authenticity.

(Based on Rodwell 1998)

These elements are summarised in Table 3.1

Table 3.1 Methodological elements of a constructivist research inquiry

Aspect of design	Methodological Element
Entry	Natural setting Prior knowledge (tacit knowledge)
Research design	Emergent design Issue - determined boundaries Purposive sampling
Data collection	Qualitative methods Human instrument Tacit knowledge
Data analysis	Inductive data analysis Grounded theory
Rigour	Trustworthiness Authenticity
Products	Negotiated results Local (idiographic) interpretations Tentative applications Case study reporting

(Based on Rodwell 1998)

Although much of the above is widely accepted the issue of appropriate quality criteria for constructivist inquiry has yet to be fully resolved. In their earlier writings, Lincoln and Guba (1985) identified a set of criteria for evaluating the trustworthiness of qualitative research, and these are often the most cited. They include: credibility (the depth and scope of the phenomena are understood), transferability (the relevance to other settings is demonstrated), dependability (the appropriateness of methodological decisions is demonstrated) and confirmability

(findings are grounded in the data). However, in a later text (Guba and Lincoln 1989), these authors highlight their own dissatisfaction with these criteria, designed as they were to parallel the conventional positivistic standards of validity and reliability. Rather, they argue that outcome, product and negotiation criteria are equally important in judging the quality of research. As a consequence they proposed an alternative set of criteria more consistent with the basic assumptions of constructivism (Figure 3.1). They term these authenticity criteria.

Figure 3.1 Authenticity Criteria for evaluating research within the constructivist paradigm

Fairness - the extent to which different constructions and their underlying value structures are obtained and inform the results. In other words, has everybody's voice been heard.

Ontological authenticity - the extent to which individual respondents' own emic constructions are improved, matured, expanded and elaborated. That is, do participants have new insights into their own situation?

Educative authenticity - the extent to which individual respondents' understanding of and appreciation for the constructions of others outside their stakeholder group are enhanced. That is, do participants now better understand and appreciate the views of others?

Catalytic authenticity - the extent to which action is stimulated and facilitated by the (research) process. In other words, is there a catalyst for change as a result of the above insights?

Tactical authenticity - the degree to which stakeholders and participants are empowered to act. The ultimate test is therefore whether real change actually occurs.

(Based upon Guba and Lincoln 1989)

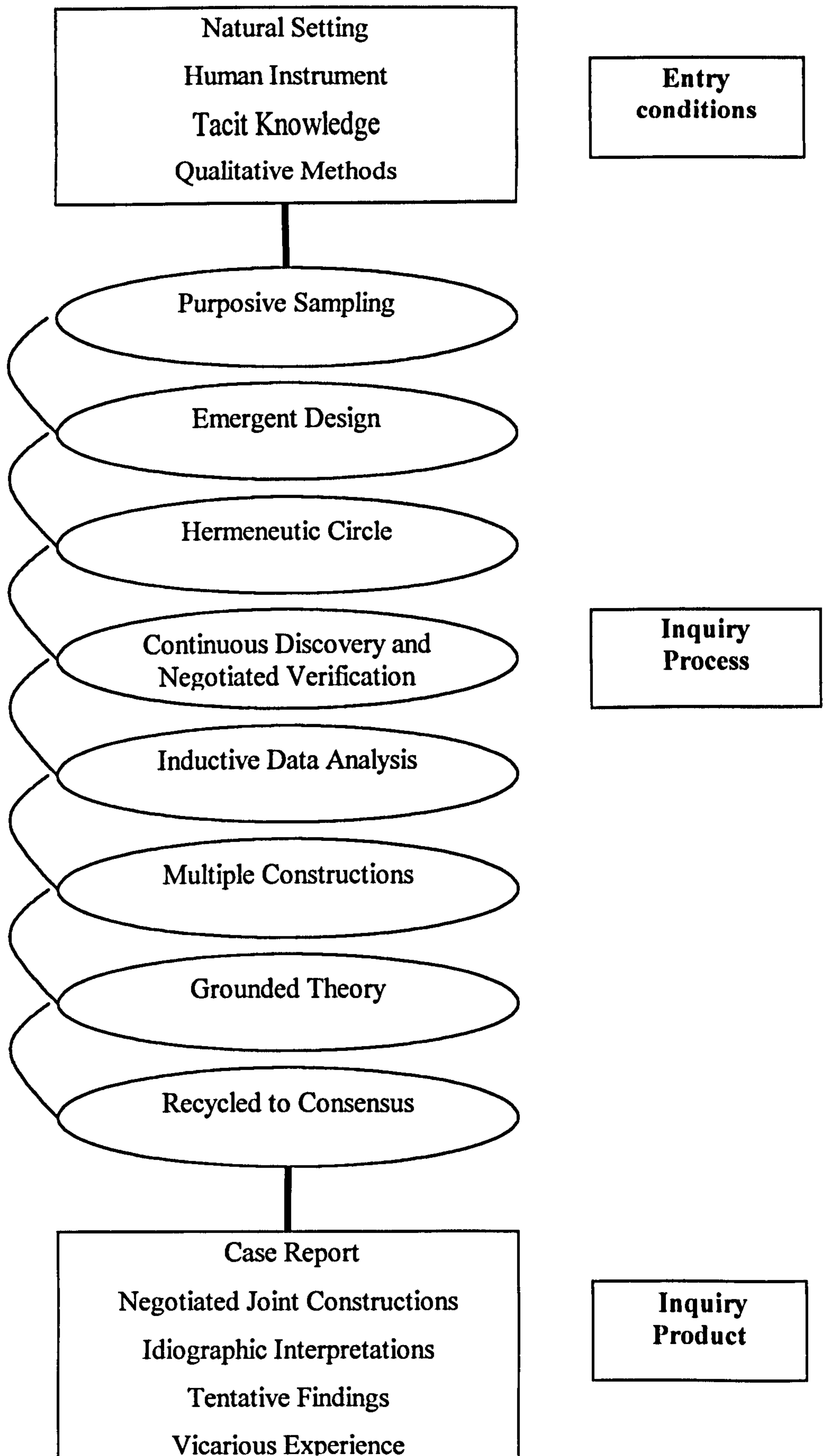
There is general consensus that an important characteristic of constructivist inquiry is that it should empower the various people who are involved in it. (Guba and Lincoln 1989, Erlandson *et al.* 1993). The credibility of a constructivist study is therefore determined in part by the extent to which it communicates the results to participants in a form that they will understand and which empowers (or potentially empowers) action. This perspective mandates an active role for the reader and obliges the researcher to produce a document that will facilitate active participation and provide a basis for developing 'working hypotheses' that can potentially be applied in other settings and contexts contexts (Erlandson *et al.* 1993). The manner in which the 'product' of the research is presented is essential and should give the reader (if they were not active participants) a sense of having 'been there'. This is termed by Stake (1995) 'vicarious experience'.

Rodwell (1998) provides a helpful diagrammatic representation of a constructivist inquiry which is reproduced as Figure 3.2, and this broadly reflects the way in which the present study unfolded. However, there was still a need to 'tailor' this approach to the particularities of the study and it is to this area that attention is now turned.

Overview of methods

In order to meet the aims and objectives outlined earlier, two discrete but related phases to the study were planned within a constructivist framework. The first phase involved semi-structured interviews with people who had experienced admission of a close relative to a nursing home. The interviews focussed upon events leading up to the admission, the experience of relocation and involvement since admission. The intention was to create a joint understanding, shared by myself and the participant, of each participant's experiences. This was an essential phase of the study as I wished to access a range of experiences and did not want to limit these experiences to particular homes. This 'broad brush' approach was intended to inform a more focused exploration within specific contexts. The second phase was intended to incorporate detailed case studies in three nursing

Figure 3.2 The Form of a Constructivist Inquiry



*Adapted from
Rodwell 1998
p 53*

homes, in order to describe everyday life within each home using participant observation and data collected in the form of field notes, interviews with staff, residents and relatives, analysis of documents and the reflective accounts of my own experiences within the setting. My intention was to locate the admission of new residents within the work of the unit as a whole, thus contextualising and illuminating the experiences identified in phase one of the study. The use of multiple methods of data collection is consistent with the basic assumptions of constructivism (Rodwell 1998). However, before the study began in earnest I considered it important to undertake some preliminary work.

Preliminary investigation

Rodwell (1998) suggests that some prior knowledge of the subject under investigation is necessary in order to determine what constitutes the natural setting for the foreshadowed questions. Given my limited experience of nursing homes, I felt it was important to undertake a period of *reconnaissance* in order to familiarise myself with the context of the study. In part this consisted of reading relevant literature in order to identify key themes and issues (see Chapter 2). However, reconnaissance also involved making informal contacts with individuals and organisations with links with the nursing home sector. These contacts included the local and regional branches of the Relatives and Residents Association; a national organisation aimed at supporting those with a relative living in a residential or nursing home. Members of the local branch provided useful comments and advice on the most appropriate ways of inviting relatives to participate in the research. Discussion with group members also provided informal insights into the problems and difficulties which relatives experience, both during the transition phase and in their attempts to establish and maintain a new caring role within the context of a care home.

During this stage, I also established contact with the nurse managers of several local nursing homes in the context of an unrelated project, and, during informal visits, sought their views on the research and on the most appropriate way to access relatives. Finally I undertook a review of a small sample of Full Needs Assessment

documentation (the approach used within Sheffield to determine eligibility for care) which provided insights into the criteria and processes for determining eligibility for social services funding for long-term placement (see Appendix I). This helped to contextualise events leading up to admission to nursing home care and the process of assessment for funding.

At this stage I also started to write regularly in a research diary (Burgess 1981), in which I made entries on anything that seemed relevant to the research: insights gained from the literature or during conferences which I attended; abstract thoughts while writing or travelling; discussions with colleagues; any thoughts which I felt it important to 'capture' to assist with the development of the study. I also made notes on the strengths (but more commonly the limitations) of the methods I was using. Occasionally I recorded my feelings about the joys and tribulations of the research. Finally I recorded ideas for taking the findings of the research further, once the thesis had been completed. The diary comprised several volumes of personal insights, some of which clearly informed my analysis and interpretation of my data, others that were later judged to be less relevant.

Phase I Creating accounts: Interviewing relatives

The first phase of the study involved interviews with relatives of older people who had relocated to a nursing home. These interviews sought to capture the meanings and interpretations of the experience for family carers.

The constructivist perspective sees the interview as a social conversation in which versions of 'reality or truth' are not so much accessed as actively constructed (Holstein and Gubrium 1995). Gordon (1998) describes this process as follows

'The process of this interaction can also be viewed as involving narrative construction, where the interviewer-researcher is actively involved in the process of developing the interviewee's story relating to the focus of the inquiry..... Interviews can be seen as interpretive practices where those involved are continually shaping and influencing the meanings which are developed. Such an

approach could be more accurately described as a process of data generation, rather than the more passive notion of data collection.'

(Gordon 1998 p78)

From this viewpoint, interviewing is a creative process in which the interactions and conversations of interviewer and respondent produce statements and formulations, rather than merely drawing such constructs from the mind of the respondent (Beer 1997). This approach to interviewing is not intended to provide a 'true' reflection of the social world that positivists strive for, but rather gives access to the meanings that people attribute to their experiences of their social worlds (Gordon 1998).

Shotter (1993) suggests that a central feature of constructivist thought is the assumption that, rather than study the 'inner psychic world' of the phenomenologists or the 'external given reality' of the positivists, we need to focus upon and explore the 'constant communicative activity that takes place between human beings'. Shotter suggests that this is an important insight for the qualitative research interviewer as it challenges the notion that what we obtain in interviews is some deep inner psychic truth or the objective truth about some observable reality. It also has implications for the way in which the interview is conducted:

'The dynamic nature of qualitative research interviewing, that is the need for ongoing adjustments in relative structure, timing, intensity and selection of informant, and in balancing flexibility, consistency, depth and breadth in data collection defies precise prediction. Such adjustments are based on experience and observation during early data collection and analysis, rather than on the investigator's knowledge and or beliefs about a content area prior to entering the field.'

(May 1991 p 195)

Developing a tool While the human instrument is the principal data collection tool in constructivist inquiry, the data collection process requires a degree of structure and form in order to produce meaningful results (Rodwell 1998). Interviews vary in their degree of organisation from the fixed or structured, in which there is a

standard order and form of questions, to the unstructured which has the appearance of a conversation. Foote-Whyte (1982) however, argues that the term unstructured interview is a misnomer and that any interview is at least minimally structured, if only by the broad area of interest of the researcher. The semi-structured interview occupies a mid-point and is guided by a series of topics or probes which are loosely constructed. The interview does not usually follow the same order or form for all informants but all relevant topics are addressed at some point.

A key advantage of the semi-structured interview as a method of data collection is that it provides access to individuals without unduly violating their privacy or testing their patience (McCracken 1988). It allows the researcher to capture the data needed for penetrating qualitative analysis without participant observation, unobtrusive observation or prolonged contact. In other words, the semi-structured interview allows us to '*achieve crucial qualitative objectives within a manageable methodological context*' (McCracken 1988 p 11).

Patton (1980) delineates six types of question for use within semi-structured interviews:

- ◆ *experience/behaviour* questions aimed at eliciting descriptions of experience, behaviours, actions and activities;
- ◆ *opinion/value* questions to find out what people think;
- ◆ *feeling* questions aimed at understanding emotional responses;
- ◆ *knowledge* questions aimed at factual information;
- ◆ *sensory* questions to determine what sensory stimuli respondents are sensitive to;

- ◆ *background/demographic questions* to understand the context in which the respondent is participating.

Within a constructivist inquiry, Rodwell proposes that the interview schedule takes the form of foreshadowed questions. These are shaped by the researcher's prior knowledge of the field:

'They are a product of the inquirer's personal/autobiographical history and conceptual work, and they are the tentative assumptions that guide the initial steps into the inquiry context. The researcher has used an inductive stance to explore all that he or she knows, including what seems to be 'missing' or 'wrong'. These questions will inevitably suggest the 'hunches' about what the researcher expects to be important in the sense making of the inquiry. This is not a theory to be tested, simply a framework from which to start.'

(Rodwell 1988 p 119)

However, over and above this guide, the nature and quality of the data collected depends in no small measure on the 'human instrument'. In other words, the interview is a skilled and delicate undertaking. Effective facilitative communication skills and interpersonal sensitivity are widely recognised to be essential elements of the interview approach and nurse researchers are often attracted to this methodology in the mistaken belief that it is simply an extension of the interpersonal skills they use in their everyday practice (Gordon 1998). Moreover, interviewing, particularly within a constructivist model, reflects parallel developments in the nature of the nurse-patient relationship, with the literature suggesting a gradual move away from traditional hierarchical research relationships towards an attempt to view research participants as partners within the research process (Webb 1989, Koch 1994). However, the potential for exploitation remains, particularly when subjects are vulnerable (Finch 1984). Careful thought must therefore be given to the skills needed for, the setting of, and the conduct of the interview. Atkinson (1993) suggests that the researcher should aim for a constructive and enabling atmosphere, in which the participant is encouraged to feel comfortable and to freely express their views and opinions. Adequate preparation,

in terms of notifying the participant of areas to be covered, and negotiating an appropriate time and setting for the interview are important factors in this respect.

Most people welcome the opportunity to talk to someone who is attentive to and interested in their lives and personal experiences. This can sometimes be an uplifting experience which increases the sense of self-worth of the participant (Coleman 1986). In fact the therapeutic potential of the formal interview has been recognised for nearly half a century:

'The formal interview is gratifying, both participants enter the conversation with explicit expectations, the one (mainly) to talk the other (mainly) to listen, which are satisfied to an extent unusual in everyday life. Moreover, the expression of opinion and the narration of fact, the playing of roles by respondents, are systematically encouraged. Resistances normally encountered in spontaneous conversation are suppressed.'

(Caplow 1956 p 18)

Certain of the challenges of qualitative interviewing have been well documented, such as the effective use of self to establish rapport and gain the trust of participants (Finch 1984), coping with the unanticipated problems and rewards of interviewing in the field (Cowles 1988, Higgins 1998), and recording and managing large volumes of data (Bryman and Burgess 1994, Ritchie and Spencer 1994). However, as May (1991) points out, other areas have received less attention within the literature. In particular May highlights the difficulty of achieving the appropriate balance between being flexible, in order to elicit an individual's story, and being consistent in questioning so that some comparison between participants can be made. May (1991) suggests that systematic preparation for each interview can help to achieve balance, including reviewing field notes from previous interviews and mentally 'taking stock' at intervals within the interview to judge whether additional questions might be needed.

Ethical issues are also frequently under-addressed when in fact in-depth interviews, particularly on emotive or sensitive topics, can arouse powerful emotions which require careful handling (Cowles 1988). For informants to experience emotional release when discussing sensitive issues is not unusual and again can in some instances be therapeutic (Nolan, 1991, Gordon 1998). However, the self-reflection, reappraisal and self-disclosure which may take place within an in-depth interview place a responsibility on the researcher to consider what provisions should be made so that the participant's well-being is not threatened (May 1991). This might include providing an opportunity to debrief following the interview or the offer of referral to another agency for ongoing support if appropriate.

An outline of the current study was submitted to the Chairperson of the Local Research Ethics Committee, who felt that the study did not fall within the remit of the committee (Appendix II). However, I was alert to the potentially traumatic nature of the memories which I would be asking interview participants to recall, and planned accordingly. It was also essential to ensure that the information provided by each participant was scrupulously protected as confidential and I attempted to ensure that no record of the interview could be associated with an individual, by coding and anonymising all data.

For the preliminary interviews with relatives, a semi-structured interview schedule was developed to reflect key themes emerging from the literature review and preliminary investigations (Appendix III). After Spradley (1979), the interview started with a 'grand tour question' (Can you tell me about the event's leading up to your relative's admission to the nursing home?). This was designed to put the participant at ease and relax them into the interview by providing a factual account of events. The remainder of the interview schedule mostly comprised of experience questions (how did you go about finding a home?), opinion questions (what role do you think you are playing in your mother's life now?) and feeling questions (what was it like for you?), with one or two factual questions as deemed relevant (did you know that you could access the inspection unit's reports?). Questions on demographic information were kept to a minimum: I tended to let participants

volunteer demographic information which they thought I would find helpful, rather than asking for it specifically. If information which I felt would be necessary to a complete account was not volunteered (for example the age of the participant and the older person living in the home, family structure), this information was sought or clarified at the end of the interview.

Rodwell (1998) advocates 'practicing' the interview in order to sense how it might unfold and how best to collect the data. With this in mind, I initially intended to treat the first interviews as pilot work. However, these pilot interviews flowed logically, the interview schedule seemed appropriate and I did not see a need to alter the process having completed two interviews. I therefore included these data within the analysis.

Finding participants My main inclusion criterion for participants was that an individual should feel that they had something of relevance to share with me, having been informed about the focus of the study. I decided to adopt as few additional criteria as possible. Accordingly, the first phase of the study involved interviews with relatives who:

- ◆ identified themselves as a close relative of someone residing in a nursing home (or who had recently died following a period of living in a nursing home);
- ◆ were personally involved in the admission process.

I initially intended to limit my sample to relatives who had experienced the admission within the previous five years, predominantly to ensure that the experience was relatively fresh in their memory. However, two individuals who replied to my newspaper advertisement (see below) were keen to participate even though the admission had taken place more than five years ago. I decided to adopt a more inclusive approach to identifying my sample and, in conducting the interviews, I began to feel that the time since admission was less important than I had anticipated and that these participants were able to recall events in vivid detail.

Within the final sample, the time since admission ranged from three weeks to eight years, although for the majority of participants the admission had taken place within the previous two years.

In constructivist investigations, the purpose of sampling is to include as much information as possible, hence maximum variation or purposive sampling is the method of choice (Patton 1980, Erlandson *et al.* 1993, Rodwell 1998). This sampling strategy aims to document unique variations that have emerged in adapting to different conditions. Within the context of the current study, use of this strategy suggested that participants should be recruited as far as possible to include experiences of a range of nursing homes and to reflect different relationships with the older person living in the home. However, practical considerations dictated that the sample should be drawn from within a limited geographical area. In the event all the participants lived within a fifteen mile radius of the centre of Sheffield. Participants were recruited using a combination of strategies (Table 3.2).

Table 3.2. Number of participants recruited using each strategy

Strategy	Participants (n)
Contact with nursing home managers	20
Advertisement in local newspaper	6
Contacts made on visits to nursing homes	3
Advertisement in Carers' Newsletter	3
Sheffield Transitional Care Forum*	3
Local branch of Relatives' Association	2
TOTAL	37

* Group comprising local practitioners and service users interested in improving care around the time of admission to a nursing or residential home

Letters to the nurse managers of a sample of nursing homes in the city area inviting them to distribute information packs about the study to relatives proved the most productive strategy. Homes were selected from the list produced by the local registration and inspection unit to include homes registered for elderly medical and elderly mentally ill (EMI) residents. A range of homes in terms of number of beds and geographical location was identified. An initial letter addressed to the nurse manager described the aims of the study and indicated that I would shortly be making contact. This was followed up with a phone call a week later when further information was provided. If the nurse manager agreed to distribute information about the study, we negotiated how many information packs I should send (usually three or four). These were then posted to the nurse manager. Each pack included written information about the study (Appendix IV), a reply slip and a reply paid envelope. Once a reply slip was received, I telephoned with more information about the study and arranged a time for the interview. I was initially concerned that identifying participants via this strategy might produce a biased sample since nurse managers might select relatives who would be likely to present a positive view of the nursing home. However, early interviews suggested that participants recruited in this way described a wide range of experiences, both positive and negative.

An initial advertisement in the local daily newspaper prompted six relatives to contact me and all were interviewed. However, a second advertisement six months later produced no response. Other participants were recruited via opportunistic contacts and through networking with service-user groups, with an item in a local carers' newsletter prompting several inquiries. Early in the study contact was made with the local social services department to explore whether they would be able to identify potential participants from their records of older people who had participated in full needs assessment. However, the relevant manager did not feel that the department had sufficient resources to do this. The final avenue of attempted recruitment, advertisements in local post offices and churches, produced no response.

Once contact had been established interviews were arranged at a time and place convenient to the participant and in most cases took place in the participant's home. Two took place at the nursing home, one at the participant's place of work and one in a local café. Arrangements were made by telephone and confirmed in writing. Relatives who had responded to the newspaper advertisement and newsletter items were also sent the information pack distributed to nursing homes, which included a brief overview of the study and an outline of the topics to be covered during the interview (Appendix V).

Conducting the interviews I took some flowers for each participant as a small token of appreciation for their agreement to take part in the study and this seemed to help establish an immediate rapport. After a preliminary period of introductions, participants were invited to read and sign the consent form (Appendix VI). At this stage, I suggested that the participant might find the process of recounting their experiences an emotional one and encouraged them to tell me immediately if they were unhappy about responding to a particular question or if they wished the interview to stop. I began each interview with a prompt along the lines of 'Can you tell me about the events leading up to your relative's admission to the nursing home?' The interview then proceeded in a conversational manner with me responding to and developing points raised by each participant. The interview schedule was used more as a checklist than a guide, to make sure that key points were covered. However, reflecting the constructivist orientation of the interviews, participants were encouraged to discuss the things which they considered to be most relevant in their own experience. Often, when the participant described a broad perception or experience, I asked if they could think of a specific example of something that had happened which influenced this perception. This proved a useful strategy for enhancing my own understanding of what the participant was trying to tell me. Throughout the interview I tried to ensure that we were creating a 'joint' understanding, both by sharing some of my own views and experiences where this seemed appropriate, and by rephrasing things they had said to check my interpretation.

As part of the hermeneutic cycle, issues raised during earlier interviews and felt to be particularly important were introduced into subsequent interviews, sometimes through the use of comparison questions, for example: 'One of things that some people have pointed out in earlier interviews is...' or 'one of the things I'm finding is.... Would you say that applies to you/reflects your own experience?' In this way, discovery and verifications were continuously interwoven throughout the periods of interviewing.

The interviews ranged in length between 45 and 115 minutes. A tape-recorder was used (with consent) in every case to record interaction for later transcription. I usually attempted to terminate the interview when no obviously new information was forthcoming, or when the participant seemed to be becoming tired (Rodwell 1998). While many participants became tearful during the interview, none requested that the interview should be terminated. However, one spouse participant became visibly upset immediately the interview began and continued to weep at intervals throughout. Although this person indicated that he was willing to continue, I felt it would be inappropriate to extend the interview and brought it to a close after 45 minutes. In each case where participants became distressed I offered to turn off the tape-recorder and provided immediate support, although none of the participants requested further support beyond the end of the interview.

Towards the end of the interview, I attempted to summarise some of the key points which had emerged and checked out my understanding with the participant. I also asked them whether there was anything else which they would like to add. This final question often produced quite useful insights into areas which I had failed to address within the interview and additional points were added to the interview schedule as a result. All participants were provided with information about the local and national branches of the Relatives Association. Where it became apparent during the interview that I had access to resources or information which the participant might find helpful, these were posted together with a thank you letter.

It transpired that for many participants, this was the first opportunity they had been offered to discuss their feelings about their relative's admission to a nursing home in detail, and many volunteered the information that they felt the interview had been beneficial. This reinforces the findings from the literature in relation both to the limited extent to which carers are encouraged to explore their feelings, and to the value that such explorations may serve (Shotter 1993). It also highlights the ethical issue of raising participants' expectations that further support may be forthcoming and reinforces the importance of being clear about the purpose of the interview (Finch 1984, Bray *et al.* 1995).

In eleven cases, another family member was present for all or part of the interview. In most cases this was a spouse or partner. In one case the daughter-in-law of a female resident was present while I interviewed her husband. Rodwell (1998) acknowledges that from time to time group interview processes may evolve when additional individuals include themselves in an interview session and highlights the need for flexibility on the part of the interviewer. I felt it was important to include these additional people within the interview as participants had indicated their desire for this by arranging for them to be present. In all cases, these 'extra' participants provided additional insights and accounts of experiences.

Verifying accounts Immediately following each interview, I prepared brief field notes describing the context of the interview together with any significant events or impressions. I then listened to the tape-recording of each interview. This was principally for the purpose of preparing a written summary to send back to the participant(s) with selected extracts transcribed verbatim (examples are included as Appendix VII). However, it also allowed me to examine the way I had phrased questions within the interview, checking for leading questions and ambiguity, and for any language which the participant may have found difficult to understand. I was then more alert to these possibilities within subsequent interviews.

The written summary was posted to the participant with an invitation to add any additional information or correct any misinterpretations. These were noted on

return. Just under half the participants (n = 18) replied to this invitation and corrections of factual details were made to the transcript if necessary. Any further reflections provided by the participant were added in the form of a memo. A complete transcript of the interview was then prepared and imported into the QSR*NUDIST project database (Qualitative Solutions and Research 1997). Further details of the analysis of these data will be described following a description of the methods used within the case studies.

An emergent research design

It will be recalled that at the outset I had imagined that the study would evolve in two separate phases, occurring sequentially. I envisaged that I would interview relatives about their experiences, analyse these data and then use my findings to inform the case study research within a small number of nursing homes. I anticipated that this would enable me first to describe and interpret relatives' experiences and perceptions without influencing them, and then to focus upon the admission process 'in context' and so shed light on the organisational and structural factors which shaped and impacted upon these experiences. However, I had failed to appreciate how important an understanding of the context of nursing home care would be to my participation in the interviews as a social construction. Having completed ten interviews, I decided that I needed to understand more about the context of nursing home care from a first-hand perspective in order to be able to create the kind of construction envisaged by Guba and Lincoln (1989) and Rodwell (1998). I needed to be able to probe from a position of knowledge about the context, and planned from that point on to undertake the case studies in parallel with the interviews. This again highlights the value of an emergent design.

The focus of the case study work also changed as the study progressed as I came to realise that admission of a new resident was a fairly rare and unpredictable event, particularly within smaller nursing homes. Having undertaken several days of observation at my first case study home without a hint of a new admission, I began to appreciate what a hit and miss affair this might be. I discussed with the nurse manager, the possibility of her alerting me when a new admission was expected;

however, although willing in principle, she was so preoccupied with her own responsibilities that I doubted that this would happen in reality. My other work commitments also meant that it would be impossible for me to 'drop everything' to observe events surrounding a new admission, particularly since the nursing home manager often did not receive notice of an admission much before the day of arrival.

I considered changing the method to pursue longitudinal interviews with relatives, following them from the period from identifying the need for nursing home care, through the process of finding a home and then following admission. However, by this stage, the interview data and early observations at the first case study site were suggesting the significance of the culture within the home in shaping relatives' experiences. I was also starting to appreciate the importance of contextualising these accounts in relation to the perspectives of residents and staff and of viewing the admission process as just one part of the total experience of supporting an older person through the transition into care and beyond. I therefore decided to re-focus the case study investigations on the culture operating within each home and in particular the relationships between relatives, residents and staff, in the expectation that this would inform my interpretation of relatives' experiences and how these could be enhanced. This re-focusing of the research design as the study progressed is entirely consistent with the methodological principles of constructivism.

Phase II: Case studies of nursing homes

Case studies were conducted in three nursing homes over a two-year period. The timing of the case studies in relation to the interviews is shown in Figure 3.3. As noted above, my original intention within this phase of the study was to explore current practice in relation to supporting relatives around the time of admission to a nursing home. However, as my appreciation of the basic tenets of constructivist inquiry developed, I realised that combining a case study approach with the interview phase of the study would provide an opportunity to ensure that all voices were heard and the views of all stakeholders considered. The case study is an 'intensive' approach to data collection and analysis and is particularly appropriate

when the intention is to study phenomena within a given empirical context (Yin 1994, Stake 1995). This methodological approach is useful for investigating complex issues where the boundaries between the phenomenon (relatives experiences) and context (the nursing home) are not clearly evident (Yin 1994).

Figure 3.3 *Timing of the case studies and interviews*

Time period	Interviews	Case studies
1998		
Jan - Feb	1 - 7	
Mar - Apr	8 - 11	
May - June		
July - Aug		
Sep - Oct	12	
Nov - Dec	13 - 19	
1999		
Jan - Feb	20 - 29	Case study 1
Mar - Apr		
May - June		
July - Aug		
Sep - Oct		
Nov - Dec	30	Case study 2
2000		
Jan - Feb	31 - 35	
Mar - Apr	36 - 37	
May - June		
Jul - Aug		Case study 3

Case study research is equated with multiple meanings (Stake 1995) and is therefore consistent with the tenets of constructivist inquiry. Multiple case study designs are particularly useful when comparison of cases is potentially fruitful (Stake 1995). In many texts on research methods, the location of the case study within the raft of methodological approaches is unclear. There are suggestions that case study is not a method *per se*, but rather a family of methods, with case study being neither intrinsically qualitative or quantitative. Furthermore, Stake (1995) suggests that case study is not a methodological choice, but rather a choice of what to study, in that it focuses on a particular instance or case. This suggests that case studies are compatible with a range of research approaches, including constructivist inquiry.

Stake identifies three broad forms of case study: the intrinsic, the instrumental, and the collective. The main aim of an intrinsic case study is to better understand a given case (for example a single nursing home). The researcher's primary interest is in the case itself rather than what it may say about similar cases, because the case is 'intrinsically interesting'. In contrast, while an instrumental approach may study one or a limited number of cases the intention is to use the data gathered to better understand a broader set of phenomena. The ability to make some inferences beyond the single case is therefore important. A collective case study involves a wider number of cases in order to enhance the range of inferences possible. Within the constraints of the current research I intended to study a small number of nursing homes in order to identify and describe factors influencing relatives' experiences which would have relevance beyond the three homes under exploration. I therefore adopted a principally instrumental approach involving a small number of cases.

Case study methods Stake suggests that the most appropriate method for qualitative case study research is to:

'Place the best brains available into the thick of what is going on. The brain work is ostensibly observational, but more basically reflective. In being ever reflective, the researcher is committed to pondering the impressions, deliberating recollections and records –

but not necessarily following the conceptualisations of theorists, actors or audiences.'

(Stake 1994, p 242)

While Rodwell (1998) proposes interviewing as the primary method for constructivist inquiry, she concedes that observation can complement the information available from interviews alone. I therefore decided that it would be beneficial to use observations in addition to interviews. In order to get the maximum benefit from the observation, and to be consistent with a constructivist approach, I adopted participant observation as my method of choice. In a seminal text, Junker (1960) describes four principal roles available to the participant observer. These can be considered as points along a continuum, ranging from complete participant, in which the researcher's real intentions are not made known to research 'subjects', to the complete observer role, in which the researcher observes from outside the setting and is not visible to participants (for example using a hidden camera). Within a constructivist inquiry, both of these roles would be rejected on ethical grounds. Between these two extremes are the 'participant as observer' role, where the researcher's intentions are known by participants but where the researcher participates fully in activities within the setting, and the 'observer as participant' role, in which the researcher observes within the setting but attempts to minimise interaction in order to avoid biasing events. The 'participant as observer' role is the only role which is compatible with constructivist inquiry since:

'...the data are created in relationship and the inquirer can check for meaning in the moment, a process not possible when complete observation is the activity.'

(Rodwell 1998, p 127)

Constructivist participant observation should be:

'...a many-sided, long-term relationship with those being observed. It involves a process of looking, listening, watching and asking into the natural context of the observation.'

(Rodwell 1998, p 127)

These comments suggest that participant observation within a constructivist inquiry should be an interactive process, with continuous dialogue and feedback between the researcher and research participants. The extent to which this was achieved within the current study is discussed in Chapter 6.

Selection of case study sites The case study nursing homes were selected purposively to incorporate variation in terms of size, resident population and geographical location. However, the Phase I interviews also informed the selection of sites. The first case study home was selected broadly for pragmatic reasons: it was geographically close to my place of work facilitating easy access for data collection. Also I had previously met the manager in the context of another study and she had expressed a willingness to participate in further research projects. In other respects, the home seemed fairly typical and, I felt, offered a useful starting point.

As the period of data collection at this home progressed, I began to appreciate that a number of constraints within this setting meant that the experiences of relatives and residents were less than optimal. These included frequent changes in personnel, including senior nursing staff, and inadequate resources in terms of basic equipment and staffing levels. In choosing a site for the second case study, I therefore felt it was important to identify a nursing home where I could anticipate that relatives experiences might be more positive, in order to provide a meaningful comparison with the data emerging from the first case study. I therefore relied on the interview data (by this stage I had conducted 30 interviews) and selected a nursing home which had been described in largely positive terms by several participants. This provided the site for the second case study.

Having completed data collection at the second case study site, I was beginning to appreciate the range of factors most likely to impact upon relatives' experiences of a particular home. Since the size of the home appeared to be an important factor in this respect, the third case study site was a small home, selected to complete the range in terms of number of resident places. This home was also identified on the basis of positive perceptions on the part of some relatives interviewed during Phase I of the study.

Negotiating access Constructivist inquiry requires the research to be undertaken in the natural setting of the phenomenon or problem under investigation (Guba and Lincoln 1989, Rodwell 1998). Johnson (1975) suggests that access to a naturalistic research setting may be negotiated in stages, while Erlandson *et al.* (1993) emphasise the importance of establishing a rapport with community leaders (in this case nursing home managers). Following this advice, I negotiated access to each home initially via the nurse manager and negotiated further involvement with individuals on a one-to-one basis. In an initial telephone call I introduced myself (I had already met the manager of the first case study site) and explained the aims and methods of the research. All three managers were willing to meet with me to discuss the research further and I posted written information about the study to each manager prior to our meeting.

At the first meeting I explained the aims and methods of the research in more detail and discussed the role which I envisaged adopting. I suggested to each manager that the most appropriate participant observer role would be for me to work as a health care assistant alongside the staff. I explained that I did not want to assume any of the responsibilities of a qualified nurse, such as drug administration, partly due to my limited experience of working in a nursing home setting, but also because I did not want responsibilities to residents to detract from my primary role as a researcher. All three managers were very positive about the research and agreed to the role I had suggested. I negotiated with each manager what I should wear during my visits. This ranged from a white coat at Nursing Home A, to a

health care assistant uniform at Nursing Home B, to my own clothes at Nursing Home C.

The intention of the case studies was to allow the identification of cultural and organisational factors which influenced relatives' experiences (an instrumental case study). I conducted between twelve and fifteen days of observation in each home over a five to six month period and worked alongside various members of staff. I also made visits to social events to which family members had been invited. The principal data collection method was participant observation within the 'participant as observer role' (Junker 1960, Pearsall 1965).

In his seminal text on observational methods, Lofland (1971) suggests that understanding within any social setting can be achieved by examining six social phenomena:

- ◆ acts (actions)
- ◆ activities
- ◆ meanings
- ◆ participation
- ◆ relationships
- ◆ settings

(Lofland 1971)

Given the themes identified within the literature review, these phenomena seemed a relevant focus for the observations and provided a loose framework guiding me to record observations and conversations of interest. During each period of field work I made brief notes and these acted as reminders for a more detailed written account of each period which was prepared once I reached home. Informal interviews were also conducted with staff, residents and their relatives as opportunities arose. Some of these interviews were tape-recorded with the

participants' permission while others were recorded as field notes. I also negotiated access to relevant documentation, including care plans, progress notes, written policies and procedures. These documents were examined and read in a relatively unstructured way during quiet periods and brief notes were made and then written up in full following each period of field work. However, on the whole the direct observation of interactions together with discussions with staff, residents and relatives within each home, provided much clearer insights into experiences of life and care than written documents.

Ethical issues The use of observation as a research method, particularly observation of people who are frail and vulnerable, raises important ethical issues. In particular, issues of informed consent, confidentiality and the observation of poor practice pose significant challenges to the participant observer. As Stake points out:

'Qualitative researchers are guests in the private spaces of the world. Their manners should be good and their code of ethics strict.'

(Stake 1994 p 244)

Madjar and Higgins (1996) suggest that the researcher within a nursing home context is required to take on the responsibility of a moral agent, adapting approaches and actions in response to the needs of others in the research relationship, rather than adhering strictly to a pre-determined ethical protocol. This is particularly relevant in relation to the need to negotiate access and informed consent to participate from people who may be cognitively frail. Entry into any field of research involves two separate phases: first, negotiation with the research participants about the nature of fieldwork and second, gaining informed consent from participants. The importance of these issues is heightened when observational methods are used since it is often difficult, if not impossible, to gain the consent of every person who is likely to enter the field during a period of observation. Furthermore, older people who are cognitively frail are likely to be overwhelmed

and intimidated by the language of research and the use of written information is inappropriate in many cases (Madjar and Higgins 1996). This requires researchers in contexts such as nursing homes to use a range of strategies to ensure that consent is maintained. Savishinsky (1995) also highlights the tensions between the formality involved in seeking written consent to participate in research and the informality necessary to reduce reactivity in the research setting.

With these challenges in mind I spent a good deal of time during the first few periods of observation at each case study site introducing myself to residents and relatives, and attempting to explain the purpose and nature of the research in straightforward terms. Given that many residents were cognitively impaired, this often proved difficult and it was sometimes necessary to repeat my explanation several times to a resident within a single period of observation. Where possible, the study was discussed with relatives and their views on the resident's likely willingness to be included in the study were sought. Information sheets about the study were available for relatives, residents and staff and I attempted to ensure that I was introduced to other professionals visiting the home such as general practitioners. However, while I am confident that I obtained informed consent from everyone I interviewed, I cannot claim that every individual whose activities I observed and described in field notes had consented to participate in the research. This point is discussed further in Chapter 6.

One of the most difficult ethical challenges of observational research within settings where health and social care is being delivered relates to decisions about appropriate action when poor practice is observed (Higgins 1998, Koch, 1995). As Schwandt points out, something of a contract exists between the researcher and the researched, a kind of moral obligation not to disclose information which may directly harm the individual concerned (Schwandt 1993). However, the non-disclosure of information may also result in harm to the individual, particularly where the researcher opts not to intervene in potentially damaging practices. At the outset of the case study phase of the research, it was difficult to anticipate what kind of situations and events would be observed. Nonetheless the extensive

literature documenting threats to personal autonomy and dignity in many settings providing care for older people, together with insights from the Phase I interviews suggested that less than optimal practice would possibly be encountered. It was therefore necessary to plan for such a contingency.

As previously mentioned, the Chair of the Local Research Ethics Committee had decided that the study did not fall within their remit and therefore did not need to be considered by the full committee (Appendix II). However, in view of my own concerns about the ethical implications of my proposed methods, I shared these reservations in a number of fora, with relatives, practitioners and other researchers. This allowed the preparation of some guidelines for my own research practice within the case studies.

I felt it was essential to be as open and honest about the purpose of the research as possible. I also decided that I would intervene if I felt that an older person or a member of staff was at risk of physical injury or serious emotional distress. Beyond this, I felt that it would be more appropriate to feed back my perceptions of less serious threats to participants' physical and emotional well-being within the case report rather than intervening at the time. The extent to which this approach was successful in challenging practice within each case study site is discussed in Chapter 6. However, by acting as a participant (rather than a non-participant) observer, I was engaged in care delivery during each visit and to some extent I role-modelled the care which I felt was appropriate. This was occasionally commented on by staff, residents and relatives who remarked that the way I spoke with residents was 'different', or that I was 'obviously cut out for this kind of work'. In other situations I attempted to complement or supplement the care provided by staff, for example moving to close a door when staff were undressing a resident with the door open, talking to a resident to try to calm them when they were distressed at being taken to the bathroom, responding to a resident's request to be taken to the bathroom when other staff had ignored them or told them to wait. By acting in this way I felt that the 'ethic of care' had not been compromised, yet I did not feel that such actions biased my perceptions of experiences of life within the home.

In practice, the approach to data collection within the case study sites worked well. I was easily accepted by most members of staff, although one or two obviously remained suspicious of my motives, for example saying (in a joking way) “*We know you’re watching us and you’ll be reporting back later!*”. On occasion, an opportunity arose to reciprocate within the setting: for example helping a member of staff with a course assignment or a job application, or taking notes for a relatives’ meeting. On one occasion, when the cleaner was off sick on the day of a relatives’ meeting and staff were obviously anxious about the cleanliness of the home, I vacuumed twelve bedrooms. On the whole, staff were extremely grateful to have ‘an extra pair of hands’ and I was usually thanked profusely at the end of each shift.

Residents on the whole accepted my presence as an ‘outsider’ and seemed pleased to have someone different to talk to. Since I was additional to normal staff numbers, I found I had time to engage residents and visitors in conversation. Most people were happy to be interviewed ‘informally’ and the periods of observation at each home produced a wealth of data. Further reflections on the ethical implications of the study methodology are included in chapter 6.

Synthesis of data arising from all the methods used within the case studies informed the development of case reports in relation to each home. The process through which these were developed is described in the next section. Further reflections on data collection within the case study sites is also included in Chapter 6, together with a critique of the approach I used. A description of the setting for each case study, together with some of the impressions and characteristics of nursing home care which influence and impact upon relatives’ experiences of nursing home entry, are presented in Chapter 5. Further synthesis of these data with the interview data is presented in chapter 6.

Analysing Accounts and Observations

The process of qualitative data analysis involves an appreciation of the way in which participants order and analyse their world (Lofland 1971 p 7). However,

this is not an easy undertaking. Marshall and Rossman for example describe data analysis within qualitative research as:

'... the process of bringing order, structure and meaning to the mass of collected data. It is a messy, ambiguous, time-consuming creative and fascinating process. It does not proceed in a linear fashion; it is not neat.'

Marshall and Rossman (1989 p112)

Part of the complexity of qualitative data analysis arises from the need to *'select paths through complex and voluminous data sets, because not all paths can be explored'* (May 1994 p12). The qualitative researcher therefore seeks guidance in the form of general strategies, techniques and frameworks which might point the way through this process. Bryman and Burgess for example (Bryman and Burgess 1994) distinguish between general strategies for data analysis (analytic induction, grounded theory) and general processes (coding, building of typologies). However, a common criticism of much qualitative research is that the processes and techniques of data analysis are not made sufficiently explicit within reports of the work. This lack of procedural transparency has led to suggestions that qualitative research is anecdotal, biased, even fabricated (Diamond 1987, Silverman 1993). In an attempt to address these concerns, a number of texts devoted specifically to the analysis of qualitative data have appeared during the past decade and various frameworks outlining the discrete steps to be undertaken have been described. On closer examination it becomes apparent that these models or frameworks overlap in a number of respects and share many common features, for example depicting the analysis of qualitative data as a continuous, iterative process (Miles and Huberman 1994, Ritchie and Spencer 1994, Denzin 1997).

The generation of concepts or categories is one of the most frequently mentioned aspects of qualitative data analysis. Hammersley and Atkinson (1983) for example recommend immersing oneself in the data and then searching out patterns, identifying possibly surprising phenomena, and being sensitive to inconsistencies, such as divergent views offered by different groups of individuals. They recognize

that sometimes the researcher will end up generating new concepts, but on other occasions will be relating his or her observations to pre-existing ideas (see Lofland 1971). Ritchie and Spencer (1994) identify six discrete functions of qualitative data analysis: defining concepts; mapping the range, nature and dynamics of phenomena; creating typologies; finding associations; seeking explanations and developing new ideas, theories or strategies. Hammersley and Atkinson (1983), Spradley (1979, 1980), Woods (1996) and others mention the building of typologies and taxonomies as an important component of analysis. Here the researcher aims to delineate subgroups within a general category (Bryman and Burgess 1994). These devices can be helpful in the identification of differences in the data and can assist with the elucidation of relationships among concepts. Differences between the components of such classifications in terms of behaviour patterns are important in generating the kinds of linkages that will form the basis for the development of theory.

Several commentators agree that while methodological texts now provide detailed descriptions of the practical techniques involved in data sorting and coding, there is less guidance on the processes used to identify conceptual relationships and theoretical propositions (Morse 1994). May (1994) goes as far as to suggest that a kind of 'magic' is involved in the way that insights and intuition on the part of the analyst inform the developing theory:

'Method does not produce insight or understanding or the creative leap that the agile mind makes in the struggle to comprehend observations and to link them together. Regardless of the paradigmatic perspective held by the scientist, the process of knowing itself cannot be observed and measured directly, but only indirectly by its product.'

(May 1994 p13)

Morse, on the other hand suggests that theoretical insights are the result of '*hard labor, persistence, data preparation, and a lot of earnest thinking and discussion*' (Morse 1994 p 6). She describes four cognitive processes that she suggests are

integral to all qualitative methods. These are labelled: comprehending, synthesising, theorising and reconceptualising. The particular qualitative approach adopted largely determines how these four processes are weighted, targeted and sequenced. Morse suggests that these cognitive processes proceed more or less sequentially within a project. However, she recognises that some *'looping backwards and forwards'* will take place as gaps become apparent. Each of these stages will now be described in more detail.

Comprehending initially involves learning everything possible about the research setting in order to *'avoid reinventing the wheel'*. This includes reference to the literature, data collection within the field, and preliminary analysis in the form of coding and aggregating data into categories. Morse (1994) suggests that the literature should be *'held in abeyance'* during fieldwork but nonetheless provides a theoretical context and rationale for the study. Comprehension is reached when the researcher has sufficient data to be able to write a complete, detailed, coherent and rich description of the phenomenon of interest.

Synthesising involves the merging of several stories, experiences or cases in order to describe a typical, composite pattern of behaviour or response. This is the stage at which the analyst sifts the data to *'weed the significant from the insignificant'*. The researcher also becomes aware of critical factors which help to explain variation within the data.

Theorising is the systematic selection and *'fitting'* of alternative models to the data (Morse 1994). It involves the construction of alternative explanations and holding these against the data until a best fit that explains the data most simply is arrived at.

'Theorising is the constant development and manipulation of malleable theoretical schemes until the 'best' theoretical scheme is developed. It is a process of speculation and conjecture, of falsification and verification, of selecting, revising and discarding. If one ever finishes, the final 'solution' is the theory that provides the best, comprehensive, coherent and simplest model for linking diverse and unrelated facts in a useful, pragmatic way. It is a way

of revealing the obvious, the implicit, the unrecognised and the unknown.'

(Morse 1994 p32).

Recontextualising involves the development of the emerging theory so that it is applicable to other settings and to other populations. At this stage the emerging theory is compared to the work of other researchers and with existing theory. The goal is to locate the findings in the context of established knowledge, both to identify findings which support existing theory and to establish any new contribution to knowledge.

Morse suggests that these four stages can be applied within any qualitative research strategy. Within a constructivist inquiry, data analysis proceeds in parallel with data collection. From the first exploration into the field, the researcher is responding to the first available data and forming:

'tentative working hypotheses that cause adjustments in interview questions, observational strategies and other data collection procedures'

(Erlandson *et al.* p114).

In this sense, the analysis is continuously developing as data collection proceeds with the principal goals of interpretation and understanding (Guba and Lincoln 1994). The task of the analyst is to develop a construction of how parts of the culture under study fit together, influence or relate to one another that represents the setting which has been explored, but at the same time sheds light on how similar processes may be occurring in other settings (Feldman 1995). This requires the analyst at some stage to begin to condense the data and impressions based upon the data into a manageable form and it is to this more structured process that attention is now turned.

In their early writings on naturalistic (constructivist) inquiry, Lincoln and Guba (1985) propose adaptations to the constant comparative method first described by Glaser and Strauss (1967). The constant comparative method of analysing qualitative data combines inductive category coding with a simultaneous comparison of all units of meaning obtained (Glaser and Strauss 1967). As each new unit of meaning is identified for analysis, it is compared to all other units of meaning and subsequently grouped (categorised and coded) with similar units of meaning. If there are no similar units of meaning, a new category is formed. (Maykut and Morehouse 1994). In the categorising and coding process, the researcher seeks to develop a set of categories that provide a reasonable reconstruction of the data collected (Lincoln and Guba 1985).

Guba and Lincoln (1989) and Rodwell (1998) suggest that grounded theory is an appropriate method of analysis within naturalistic research. Morse identifies the four cognitive processes in relation to grounded theory generation as follows:

- ◆ Interviews (*comprehending*)
- ◆ Coding, memoing, analysing negative cases, theoretical sampling (*synthesising*)
- ◆ Development of typologies, model/theory development (*theorising*)
- ◆ Development of substantive theory/development of formal theory (*recontextualising*)

(Morse 1994)

The way in which my approach to analysis reflected these four stages will now be described in more detail.

Analysing the interview data In analysing the transcripts of the interviews I used the procedure described by Lincoln and Guba (1985) and Erlandson et al. (1993) while trying to remain true to the tenets of the constructivist approach as described by Rodwell (1998). I found it helpful to consider my progress in relation to the

stages described by Morse outlined above. The approach to analysis was inductive, and sought to develop theoretical propositions which would accurately reflect the participants feelings, thoughts and actions (Maykut and Morehouse 1994). Essentially, I was looking to identify a range of experiences and ways of behaving (typologies) that might inform health and social care practice. However, I was also mindful of the need to analyse and present the data in a way which would have the potential both to inform and empower older people and family caregivers.

For pragmatic reasons, detailed analysis of the data was undertaken in stages following each batch of interviews. However, analysis was essentially ongoing as reflective field notes and the written summary of the interview were prepared following each interview. This phased approach to data analysis is consistent with the approach outlined by Lincoln and Guba (1985).

Lincoln and Guba (1985) suggest that the initial process of data analysis proceeds in four stages:

- ◆ unitising - locating units of meaning within the text;
- ◆ categorising - taking all the units of data and sorting them into categories of ideas;
- ◆ filling in patterns - searching for convergent and divergent opinion and seeking explanation for these discrepancies;
- ◆ member checks - feeding back the categorisation to participants.

Use of the QSR*NUDIST programme (see Appendix VIII) rendered the processes of unitising and categorising data swift and efficient. Each unit consisted of either a few words, a sentence, several sentences or in some cases a paragraph. Lincoln and Guba (1985) state that units must be heuristic, that is they must be aimed at some understanding or some action that the inquirer needs to have or to take. They must also be the smallest piece of information about something that can stand by itself. In other words they must be interpretable in the absence of additional

information, other than the broad context in which the data were gathered. It was at this stage that 'leads' from the literature review began to come into play as I recognised concepts and meanings previously described.

In analysing the first ten interview transcripts, I created free codes; that is units of text were coded in a largely descriptive manner using codes to represent the meaning of each fragment. As many separate codes as were needed to describe the data were generated and no attempt was made to force a fragment into a code: if it did not fit existing codes then a new code was created. This process resulted in the generation of more than 400 separate codes and by this stage the process was becoming unwieldy. Categories were then grouped under a series of headings and sub-headings to form an initial framework (Appendix IX). This framework was essentially quite descriptive but allowed for easy identification of codes and categories. The next fourteen interviews were then coded and again a large number of free codes were added to the framework. I then spent some time considering each code and the data which was attached to it in order to begin to group codes into broader categories. At this stage the descriptive framework which had been developed on the basis of the first ten interviews was modified and new categories were created to reflect sensitising concepts (Blumer 1954, van den Hoonaard 1997).

Sensitising concepts are constructs derived from the research participants' perspective which sensitise or alert the researcher to possible lines of inquiry. Van den Hoonaard likens them to 'half-way houses' where data are stored temporarily and made ready for further analysis (van den Hoonaard 1997). He compares them with 'folk' concepts - roughly equivalent to the participant's definition of the situation, whereas sensitising concepts are the analyst's 'definition of the definition of the situation'.

Again the data attached to each code within each category was reconsidered in order to generate category titles and descriptive sentences. I attempted to write inclusion criteria as propositional statements (Lincoln and Guba 1985), as a way of beginning to develop theoretical ideas that would start to explain relatives

experiences (see Appendix X for examples). At this stage, some merging of codes began to take place but each broad category still had numerous sub-categories.

At the same time as data were extracted from each interview and aggregated in relation to categories, I attempted to maintain the integrity of each case by entering key categories onto a matrix for each participant so that linkages between themes could be examined. This adaptation was designed to overcome Lincoln's criticism of the process of decontextualisation as reductionist (Lincoln 1992). Examination of key themes could then proceed in parallel, comparing similar cases using the aggregation of data under the category headings and tracing the development of themes in relation to an individual participant's experiences. This process also facilitated the development of 'meta-themes', which began to build into a framework for representing the range of experiences described within the study.

Lincoln and Guba (1985) offer four criteria for deciding when sufficient data have been collected and analysis is complete: exhaustion of sources, saturation of categories (continuing data collection produces tiny increments of new information in comparison to the effort expended to obtain them); emergence of regularities (a sense of integration - although they warn against drawing to a close as a result of regularities occurring too early in the process); and over-extension (the sense that new information is very far removed from the core of any of the viable categories that have emerged without warranting the addition of new categories). In relation to analysis of the interview data, the final three interviews added few new insights, and while providing further examples, did not result in adjustment to the categorisation framework. At this stage it was considered appropriate to cease data collection. The case report was then constructed around the meta-themes using a narrative style and attempting to ensure that voices of all participants were represented.

Analysis of case study data As mentioned previously, analysis of the case study data began with the first foray into the field, with the detailed recording of observations and perceptions, sometimes in the form of tentative theoretical

propositions. These notes were revisited and modified following each period of data collection in an interactive refining process. Once data collection at each site was complete, detailed analysis of the case study data then proceeded in three stages:

1. analysis of data relating to each home (within case analysis);
2. analysis of data across homes (cross case analysis);
3. integration of the case study data with the interview data.

The intention of the single case analysis was to construct comparable accounts of the structures and processes influencing the experiences of relatives within each nursing home. However, this proved to be a complex undertaking. Becker and Geer for example (1982) highlight the particular challenges of analysing data gathered during periods of participant observation:

'What is the participant observer with his file of 'rich' but unsystematic data to do? He knows a good deal about the organisation he has studied, and he has a great deal of confidence in many of the conclusions he has drawn. But how does he present his conclusions and the evidence so as to evoke in other scientists the same confidence he himself feels.'

(Becker and Geer p 240).

Rodwell (1998) suggests that, in most cases, the data from observations are not entered into the raw data that will be unitised for analysis (as with the interview data). Rather they are used as 'background' to extend depth and scope in the meaning making and reconstruction. This assertion fitted my own intentions for the case studies and suggested that it would be inappropriate to unitise and categorise the observational data as I had the Phase I interview data. However, in a pragmatic sense, Rodwell's description provides little guidance on practical techniques for the analysis of observational data within constructivist research and I needed to search elsewhere. As mentioned earlier Lofland (1971) suggests that understanding can be achieved by examining the six social phenomena of:

- ◆ acts (actions)
- ◆ activities
- ◆ meanings
- ◆ participation
- ◆ relationships
- ◆ settings

(Lofland 1971).

These phenomena had provided a prompt for recording my observations and reflections and also served as a useful starting point for analysing the observational data. The analysis was broadly tuned to the identification of practices which support or inhibit relatives in achieving a smooth transition to nursing home care. In exploring the field notes, interview transcripts and theoretical memos, the potential for developing 'chains of evidence' soon became apparent (Miles and Huberman 1994, Yin 1994). For example, it quickly became evident that features of the environment (setting) could have important consequences for the frequency of contact between relatives and staff (relationships). Similarly, working patterns (activities) appeared to have implications for relationships between staff and residents and vice versa. Detailed analysis of the case study data therefore involved locating these chains of evidence throughout the observational field-notes and transcripts of interviews at the case study sites. These then provided the basis for the individual case reports. Once each case report had been prepared, it was shared with participants at each case study site in an attempt to ensure that it represented a shared construction. Further details of the procedures for negotiating the case reports and my own reflections on the degree to which these procedures were successful are included in Chapter 6.

Once the case reports had been prepared, similarities and differences between the three case study sites could be identified and propositions about the potential reasons for these differences were developed. The extent to which these

propositions resonated with the interview data from Phase I of the study was also considered in order to produce a synthesis of findings from both phases of the research. This resulted in the development of a typology of models of care delivery within nursing homes, representing the main theoretical representation to emerge from this phase of the study.

Drawing the data together By this stage I felt that I had accomplished the first three of Morse's stages, i.e. comprehending, synthesising and theorising. The results of this process are presented in Chapters 4, 5 and 6 and elaborated in Appendices IX and X. The final stage, recontextualising, involved holding up my developing framework against the literature to check for consistency, and for new information that might add to the body of knowledge about relatives' experiences of nursing home care. The outcome of this process is also described in chapter 6, together with a detailed reflection on the procedures for ensuring rigour within the research.

CHAPTER 4. FINDINGS: INTERVIEWS WITH RELATIVES

Overview

This chapter presents the analyses of the data from 37 interviews undertaken with 48 relatives. It begins with a brief description of individuals within the sample and goes on to consider the experience of nursing home placement in terms of three distinct but related phases which provide a temporal account of how events unfolded. These three phases have been termed ‘making the best of things’, ‘making the move’ and ‘making it better’ and they describe sequentially relatives’ experiences: leading up to the move into the nursing home; the period immediately before and after the move; and lastly, relatives’ efforts to engage staff in the homes and contribute to the life of the resident older person in an on-going fashion. Throughout each of these phases relatives’ efforts were primarily motivated by their overwhelming desire to try and ensure that the older person received the best care possible. This has been termed ‘wanting what’s best for them’. The analysis of the data suggested that the extent to which these relatives were able to translate ‘wanting what’s best’ into ‘getting what’s best’ can be understood primarily in terms of the interaction of five sets of factors (Figure 4.1). These are the extent to which relatives felt they were:

- ◆ operating ‘under pressure’ or not;
- ◆ ‘in the know’ or ‘working in the dark’;
- ◆ ‘working together’ or ‘working alone’;
- ◆ ‘in control’ of events or ‘losing control’;
- ◆ ‘supported’ or ‘unsupported’ both practically and emotionally.

Figure 4.1 Relatives experiences during phases of the admission to a care home

<p>No pressure</p> <p><i>Being encouraged to take time to make decisions, to be yourself, to say what you want to happen</i></p>		<p>Feeling under pressure</p> <p><i>Feeling the need to make decisions quickly, to conform, to conceal your own needs</i></p>
<p>Being in the know</p> <p><i>Having access to all the relevant information to play a full and active role in the life and care of the older person</i></p>		<p>Working in the dark</p> <p><i>Lacking the relevant information to continue to play a full and active role in the life and care of the older person</i></p>
<p>Working together</p> <p><i>Being able to work with health and social care staff and with family to ensure best care for the older person</i></p>		<p>Working apart</p> <p><i>Barriers exist to working together with health and social care staff or with family members</i></p>
<p>Being in control</p> <p><i>Being able to maintaining ownership of decisions about your future and the future of your relative</i></p>		<p>Losing control</p> <p><i>Feeling that decisions have been taken out of your hands, that you can no longer influence events</i></p>
<p>Feeling supported</p> <p><i>Feeling that others are aware of the consequences of the move for you and your relative and are willing to listen to you, feeling that others are there for you</i></p>		<p>Feeling unsupported</p> <p><i>Feeling that your own experiences and/or those of your relative are of little consequence to others</i></p>

As will be demonstrated, these factors are conceived of as continua which manifest themselves in differing ways at differing points in the transition. Moreover, although they relate primarily to relatives, it is also clear from the data that similar factors impinge on staff in both hospital and community settings, and particularly in nursing homes. As was indicated in the preceding chapter, the emergent design upon which the study was based enabled the interviews and the case studies to take place concurrently and this was important in understanding the dynamics between the above five factors for both relatives and staff.

The chapter is organised so that each of the phases of the transition are considered temporally using the interaction of the above five factors to account for differing patterns within the data. However, it is important to note that although there are clear examples of each of these patterns no one relative's experience represented a perfect 'type'. Therefore, none of the participants felt totally free of pressure, fully informed, absolutely in control of events, completely supported, or worked in perfect harmony with other key players. Conversely, none felt under unremitting pressure, totally uninformed, absolutely out of control, completely unsupported, or entirely isolated. Nevertheless, all the experiences could be located relative to these 'ideal' types, with many of the relatives' accounts approximating most closely with the less well supported end of the spectrum. Before considering the first phase of the transition brief attention is given to the characteristics of the sample.

Sample characteristics

A total of 37 interviews were undertaken involving 48 relatives. A summary of the relationships of the main participants to the relative admitted to a nursing home is shown in Table 4.1 with further details included as Appendix XI. For sixteen of the participants (eleven spouses, four adult children and one niece), the older person had been co-resident prior to their admission to the nursing home.

Table 4.1 Relationship of participant to older person living in a care home

Relationship to older person	n
daughter	18
husband	7
son	5
wife	4
niece	2
nephew	1
TOTAL	37

‘Making the best of things’

Having briefly outlined the nature of the sample, consideration is now given to the events leading up to the decision to seek a nursing home placement, and a search for the actual home. Together these two activities are captured in ‘making the best of things’.

According to the relative interaction of the five factors described above, three broad types of pre-admission experience could be discerned in the data. The theme adopted for this phase ‘making the best of things’ reflects the fact that even in the more positive of admissions some difficulties were still encountered, whereas in the worst circumstances it was often a case of ‘making the most of a bad job’. The three broad experiences discernible in the data have been termed:

- ◆ **making** the decision – this relates to instances where there was a relatively proactive and planned approach to deciding that placement was needed;
- ◆ **reaching** the decision - where a decision was not made on a planned and rational basis, but rather **reached** following a period of indecision;

- ◆ **realising the inevitable** - when decisions were precipitated by a crisis and the decision to admit was neither made nor reached, but rather accepted.

By way of introduction, each of these patterns will be described in more detail and illustrated with reference to an individual relative's experience. The first pattern involved a slow deterioration in the older person's condition and/or abilities accompanied by a gradual process of decision-making so that a crisis admission was avoided. Such admissions to long-term care typically followed a period of repeated admissions for respite care and then a joint decision involving all the family, followed by an acknowledged trial period. This pattern of events allowed the older person to make their decision gradually, without pressure, and for all parties concerned to be confident that permanent placement in that particular home was the right choice. This was the case in Joan's experience.

In 1998, Joan and her husband decided that they would like to take a short holiday abroad, but were concerned about how Joan's father Arthur, who lived nearby, would cope without them. A new purpose-built nursing home had recently opened in the neighbourhood and they all went to look at it with a view to respite care for Arthur while they were away.

"So we went round and looked at it, and we were most impressed, the facilities were wonderful. The staff who we met were absolutely super."

They planned with Arthur and his GP that if anything happened while they were away, he could be admitted to the nursing home. On this occasion he didn't need to go in but a short while later Arthur became unwell when Joan and her husband were planning a short trip abroad. They planned a respite admission to the nursing home at Arthur's suggestion so that he could be settled in before they went away.

"So we rang up, and because they're not full, they said 'Oh yes bring him down this afternoon'. Which was wonderful, so we packed his bag and took him down, and it meant that we were able

to see him settled before we went away, and that was smashing, and he came home having obviously been very well looked after. And on the Sunday he came for lunch and he said, 'I nearly rang you up last night'. So I said 'Ooh why have you waited?' 'I nearly rang you up to take me back in'. So I said, 'Oh did you? Did you miss it?' He said 'Yes'. And I think it was the fact that he doesn't sleep very well, he wakes a lot in the night and then he lies and worries in the night. And there, at the press of a button, there's somebody"

They arranged several more respite admissions to cover other short breaks and then began to talk about the possibility of permanent admission.

"And so he said 'Yes, I think I'm ready to do that'. And then he had even more not very wells, and by May it was obvious that he wasn't really coping terribly well. So, I said 'Well, why don't you think about staying now?' So, he went in, with the view of this was going to be permanent, and we left things for a month and he seemed very happy so I said 'Well do you want to make it permanent now?' And he said 'Yes, I, I think I do.' So I said 'Do you want us to start, thinking about selling the flat?' 'Yes you do that then.'"

In Joan and Arthur's case, they were able to plan his admission gradually and were able to make the decision together. Arthur's GP and staff at the home were supportive throughout and allowed them to maintain control of the decision. In part, the degree of control which Joan and Arthur were able to retain over the process of admission was due to the fact that Arthur was able to self-fund his nursing home care. This meant that there were no externally fixed limits to the cost of the placement and that Arthur did not have to demonstrate that he met local authority funding criteria for nursing home placement. Arthur's gradual deterioration meant that a crisis admission could be avoided and he was able to be fully involved in the decision, reducing the pressure on Joan.

The second pattern involved a gradual deterioration in physical or mental capabilities until a critical point was reached when the older person and/or their relatives realised that they could no longer cope at home. The pattern of gradual deterioration was sometimes accompanied by repeated admissions to an alternative care environment for respite care. In this scenario the final decision to move into a care home permanently followed a crisis event which seemed to 'tip the carer over the edge' with the result that they decided they could no longer cope at home. This was Kate's experience.

Kate had cared for her mother and two elderly aunts, all three of whom lived together for several years. Within a period of six months, both aunts died and Kate's mother developed Alzheimer's disease. Kate tried to maintain her mother in the house she had shared with her aunts for as long as possible. However, she was increasingly worried about her safety. Kate's mother was attending a local nursing home for day care, with a view to permanent admission should the need arise. However, Kate began to feel that she would prefer her mother to be nearer to her.

"So I brought her to live with me. But she wasn't sleeping and she was getting up during the night. I was worried about the toilet situation. I could hear her. I wasn't getting any sleep. I was always feeling tired. And although she was happy to be with me and felt more settled, I just felt how could I sustain this?"

Although Kate managed to arrange incontinence supplies for her mother, this aspect of her illness was particularly difficult to cope with. Eventually, a crisis point was reached:

"And it came to a head one morning about seven o'clock, I opened the door and there she was, she was shivering in her night dress, and goodness knows how long she'd been there, but there was excrement all over. She'd rubbed it into the floor, all over the walls, and I found it very distressing actually. And it was hard to

pull myself together, but I just had to. And mum was distressed and shivering and I just had to try and get her into the bathroom and try to get her washed. And just shut the door on what had happened. And then tried to ring up the services, the nurse, and then it was organised, the respite for her for two weeks, an emergency measure while I looked around at homes.”

Managing incontinence, going without sleep and coping with wandering behaviour were mentioned frequently as aspects of caring which relatives found particularly difficult to deal with. Lack of support in dealing with these aspects and their emotional sequelae frequently contributed to the decision that alternative care arrangements needed to be made. In Kate’s situation, she was unable to share the decision about long-term care with her mother and was receiving little support from community services. No one had discussed long-term care options with her and she felt she was largely *working alone*. Her mother’s wandering and soiling behaviour eventually resulted in unbearable pressure which encouraged her to reach the decision that permanent long-term care was the only option.

The third pattern involved a more sudden deterioration or an acute crisis, usually requiring admission to hospital for acute treatment or assessment. The decision was then made, often by health or social care practitioners, that nursing home placement should be sought and in most cases the older person was transferred directly to the nursing home without ever returning home. This pattern was illustrated by Sally’s experience. Sally had continued to care for her husband at home following his diagnosis with Alzheimer’s disease. Her account of events leading up to her husband’s admission to full-time care is best presented in her own words:

“And he went for a week into Highlands (for respite care). And when he came home he says ‘Sal, if you ever send me there again, I’ll kill myself.’ And, because I didn’t go up... I could have gone up but they said ‘We’d rather you not’, you know. Because it was only

a week like. Anyway that was that. And then, you know, he was beginning to get worse and worse, and wanting to go down to where we'd lived before. He was going back all the time, you know in his mind, years ago. And I tell you, Michelle (social worker) came again and she said 'Will you let him go in Sally? (for respite care)' 'Oh' I said 'I daren't.' I said 'he didn't like it'. And she says 'Well you must have a rest.' So, I says 'Oh all right then'. And he weren't too bad, then. And he was sat in that chair and he thought he were going for the day, when I packed him some clothes up and that, put them in a little case, and, oh I was in such a state. And I said to, when they came for him, 'Don't let him see that case, please, while you get in there....' So anyway he'd been there about an hour and a half and the phone rang. And they said 'Oh, is that Mrs. Smith? I said 'Yes'. They said 'We've taken Mr. Smith to (name of hospital).' I said 'Ooh dear, what's happened?' She says 'Well he's got a bit of a rash on him'. Well I think, it were his nerves like. I never really got to know. And they said 'We've sent him there.' And then, er, I don't know whether they sent him straight to Hazeldean (assessment centre). Do you know I can't really remember. But they never asked my permission, you know. And they kept him there, two months, nearly two months. And you know I kept thinking Ooh they're doing something, and he's going to come home because I didn't like to ask them anything, you know, I just sat there when I went and sat right quiet. And anyway, they said like 'Oh Doctor Betts is coming today and she wants to see you Mrs. Smith.' And she just said 'Oh, Mrs. Smith, erm, these papers are telling me the names where Ernest can go.' And I says, 'Well what do you mean?' She said, 'Erm, well to get him in a home'. So I says 'Won't he be able to come home no more?'. And she said 'No' [she starts to cry].

The most striking feature of Sally's experience is that she obviously felt that the decision about long-term care had been taken completely out of her hands. While

she seems to have received support from her social worker, there was little evidence of joint decision making in her account. Throughout her husband's period in hospital, she felt *in the dark* about what was happening to him. Since she could not involve her husband in the decision and had no close family members, she described a process of realisation and acceptance in coming to terms with her husband's admission, rather than a process of active decision making.

The first pattern of gradual decision-making appeared to be associated with the most positive experiences of the move. The sense of being in control and working together with health and social care staff helped to avoid the emotional roller coaster described by many participants. However, this pattern was described by only three participants in the study. Even where admission to a nursing home had been considered and adopted as a long-term choice by the older person, the actual admission usually took place within the context of a crisis situation, often following hospitalisation, with the result that the choice of home was made in a rush and subsequently was found to be unsuitable. This was the most common pattern described by participants within the study, reflecting 29 of 36 family experiences (two relatives were interviewed from the same family).

During this initial phase of the transition process, relatives were motivated by two main concerns: they wanted to make the best decision between the options for long-term care and they wanted to choose the **right** nursing home. Experiences in relation to these aspects of decision making will now be considered with reference to the continua mentioned in the introduction to this chapter.

Under pressure / no pressure In making decisions about long-term care options, relatives were often under pressure to reconcile a number of competing factors and interests. These included the views of the older person, views of other family members, the opinion of service providers and their own needs as the primary carer. In some cases the participant had promised the older person that they would never have to move into a nursing home. Alternatively, participants felt a responsibility to continue to care for the older person for as long as possible as a consequence of familial ties. Most described a sense of duty, wanting to '*do the*

right thing'. Most perceived 'the right thing' as struggling to support the older person at home for as long as possible:

"We have had a lot of arguments....you tend to think that it is your responsibility. You're battling with your conscience. You should be doing it - you shouldn't be passing your responsibilities onto somebody else."

Betty, Daughter-in-law, Interview no. 3

Conversely, some participants were influenced in their decision by the fact that their relative needed a level of care and expertise that they were unable to provide. In such a context, helping the older person to move into a nursing home was the right thing to do:

"The only way we sort of came to terms with it was that she was in a lot of pain. And both me and my sister said that we're not nurses, and we could do a lot more harm than good. And we said, as we saw her getting weaker, 'We can't do this, we need specialised care', and she knew."

June, Daughter, Interview no. 29

In each case, the person interviewed had played a major role in helping the older person to make the decision about long-term care. However, often this responsibility was shared with other family members who occasionally held quite different views about what should be done. This often increased the sense of pressure as family members *'battled it out'*. One son, whose sister had been very against the move into permanent care, felt that health service personnel should have intervened to force the issue. More commonly, the person interviewed felt that they had carried the major burden in decision-making with other family members playing a less significant role. For a small number of relatives, there was

also pressure from less involved family members who did not always appreciate the demands and needs of the older person:

“The brother in Middlesborough, they don't know her condition at all and they were a bit against it. But later they said ‘We didn't realise’. They said ‘You can send her up to us for a few weeks’. But they are invalids themselves and they just don't realise. Nobody knows. But I'll be quite honest, nobody knows what it's like until it happens to you.”

Ruth, Daughter, Interview no.13

Other sources of pressure included the negative views of nursing homes, held both as a consequence of media attention and in some cases personal experience. For some participants these views and images were instrumental in encouraging them to try to defer their relative's admission to a nursing home for as long as possible. Nigel for example described how he tried to delay his father's transfer from an acute hospital ward to a nursing home as he was convinced that his father would continue to receive higher standards of care in the acute ward:

“I'd got flu. So I didn't want to go round any nursing homes with flu. The rest of the family didn't want to know. I tried approaching them - ‘No, we'll leave it up to you.’ So that was my excuse, I couldn't go to a nursing home, and basically I made it my excuse. I put it off for two or three weeks, I got better, but I kept putting it off because in my mind he was going to get far better treatment in hospital than he is in a nursing home. Because I'd actually been round nursing homes when he'd been into respite care, and what I'd seen, I didn't like. He used to go to one at B for respite care, out in the country, and as soon as you walked in the door there was the smell of urine. Every home that I went in always seemed to be

full of little old women, never used to be any men in, and they (the homes) smelt basically.

Nigel, Son, Interview no. 26

Collectively, the factors described above were generally experienced as competing pressures. In fact, for most participants, they were in such opposition to each other that there was no ideal solution and whatever decision was reached would necessarily represent a compromise, with the relative weighting of individual factors depending on each unique set of circumstances. However, the views of service providers were particularly influential and often appeared to have tipped the balance in favour of nursing home admission. In this sense, the decision was commonly 'expert driven'. The views of medical practitioners were especially persuasive: in a number of cases, the expressed opinion of family doctors and hospital consultants that nursing home care was the only viable option seemed to have persuaded the family to take this course.

Once the decision to pursue nursing home care had been made, reached or accepted, many participants also experienced competing pressures in relation to finding a home and again needed to weigh up a range of factors. Most relatives felt a heavy burden to make the right choice, particularly where the ability of the older person to make the decision for themselves was limited. For two families the logical choice was the home that had provided respite care, as the older person had become familiar with it. In five cases a 'default mechanism' seemed to operate: an emergency placement was found to alleviate a crisis situation and this placement then became permanent. This obviously precluded any real possibility for exploration of all available options.

For other participants the process of visiting homes in order to make the best choice was time-consuming and expensive. In assessing each home, relatives were trying to weigh up a range of factors including distance for travelling, cost and availability of activities. Other aspects repeatedly mentioned included an absence of odour, good décor and comfortable furnishings, and the rather

intangible 'feel' of the home. Most participants also considered the condition of other residents as a clue to whether their relative would be happy. All the participants wanted to be able to visit their relative regularly so the ease with which they would be able to make the journey was an important factor. However, this was often balanced with a need for the older person to remain within a familiar location as far as possible so that friends and neighbours could also visit. Difficulties in arranging transport sometimes resulted in the older person moving permanently into the home without ever having visited, placing even more pressure on the relative to make the right choice. Pressure was also a consequence of the extent to which they felt they were able to work collaboratively with service providers which will be considered in the next section.

Working together / working alone The extent to which participants felt that they were able to make decisions about long-term care options in collaboration and negotiation with others was an important factor influencing experiences during this phase. The majority of participants were caring for an older person who was too cognitively impaired to take an active part in decision-making. The effect of this was to increase the sense of responsibility for the relative and hence the burden of guilt, particularly when other family members did not play a major role in decision-making. Indeed some participants continued to reflect on whether they had made the right decisions, sometimes for years following the move.

The opportunity to work together with community services, which might have enabled the older person to continue to live at home, was another important factor in the decision for some participants. Many participants were unaware of the kind of support that might have been available and in most cases could not recall a community package having been offered. For others, a shortfall in the availability or acceptability of community care meant that admission to a care home was the only realistic option. Reg's experience of struggling for two years to support his wife at home as she became increasingly disabled and uncooperative as a consequence of Alzheimer's disease provides an example. Reg described how he had discussed with his social worker what kind of support would be useful to him:

SD ("Did you get any help from the social services?")

"No, no, they offered. But I didn't know what they could do and I said 'What can you do?' She said 'Well we can get her dressed in the morning', because that's where I was having a problem. I says 'Fair enough, but what time are you going to come and get her up?' She says 'Well what time do you want me?' I says 'I don't know, she gets up any time; pick a time from two o'clock in a morning onwards.' I says 'I know you can't come'."

Reg, Husband, Interview no. 19

A small number of co-resident participants suggested that community care would not have been an appropriate option as they would have resented the presence of carers in the house 'round the clock'. In the context of their relative needing 24-hour care, admission to a care home became the only realistic option.

Being in control / losing control For some participants, the lack of opportunity to work collaboratively with service providers to make the most appropriate decision resulted in a sense of losing control over the situation. In particular, the dominant voice of health care professionals, particularly medical practitioners caused relatives to feel that the decision about long-term care options was 'out of my hands'.

"Anyway he went into hospital for some reason and they decided while he was in hospital that they would assess him. That was the first assessment he had ever had. They came up to the flat where he was living, the social worker, there was a house-full. They completed an assessment of his needs. They decided at the end that they couldn't do it. The woman (her mother) had been doing it on her own for years but they couldn't do it with all of their resources, so he would have to go into a home. We had no choice, we didn't

know anything about anything. This social worker said where he would go and we had nothing to do with it."

Mary, Daughter, Interview no. 10

Working in the dark / being in the know Often, the sense of losing control during this phase of the move was compounded by a lack of information. Lack of awareness of possible alternatives to nursing-home admission meant that most relatives were dependent on health and social care practitioners to inform and guide them about what was available, and such information and support was frequently lacking. A small minority had prior knowledge of 'the system' or had the resources to seek out information themselves. This '*being in the know*' put them in a much stronger position to negotiate an appropriate package of care.

For some participants the experiences of *working in the dark*, *being under pressure* and *losing control* combined, with the result that they were almost overwhelmed by events. In these cases, the relative appeared to accept the decision of 'experts' that their relative should move into a nursing home, but with a great deal of accompanying distress. However, it became apparent that, within the context of decision-making, the negotiating style adopted by the relative could influence their experiences. Some relatives for example engaged in a lengthy battle to try to explore alternatives and retain a sense of *being in control*.

"It was getting to the point where every time I went to the hospital, they'd ask me to come into the office. And it started with one of the nurses - 'We don't think your dad should be going home, we think he should be in a home'. And then when that didn't work, it was the staff nurse and when that didn't work it would be a doctor and finally I said 'I want to see the consultant.' And I went to see him in his office and I said 'I'm just getting fed up with this.' I says 'Every time I come down they try to persuade me.' I says 'He's not going in a home, I don't want him in a home.' I says 'As far as I'm concerned he's mentally capable', which he was. I mean up to him

going into the hospital in July 1998, he was fine, as far as I was concerned. He had a very good quality of life. If he'd have gone into the home when the hospital wanted him to go in, there was seven months difference. So that would be seven months that he would have lost."

Nigel, Son, Interview no. 26

The sense of *working in the dark* and of *losing control* over decisions was also a common experience in relation to the choice of a nursing home. Some relatives were surprised to find financial barriers to selecting what they felt would be the most appropriate home, with high fees often leaving a shortfall between the amount available from social services and the cost of the desired home. Some found that their relative did not meet the nursing home's criteria for admission, for example, if they were visually or cognitively impaired:

"So I had to go on this long trek of finding somewhere and I found that very traumatic, because a lot of places they suggested that the matron in charge went into the place where she was to assess her and what they evidently did - they sat back and watched and I thought that isn't very good is it... I don't think she knew. But she obviously showed herself in a bad light and they refused to have her."

May, Daughter, Interview no. 4

These barriers were largely unanticipated, again contributing to relatives' perceptions that decisions were outside of their control. The operation of market forces within the continuing care sector, rather than increasing consumer choice, was perceived as a barrier to informed choice by many participants:

"...because it's a business now and people want to sell it to you. And its people want to spend ages telling you every little thing

about their home and why it's better than the one down the road. And then they'll come to the price just as if they were selling double glazing, telling you that 'Oh yes but actually it is a little bit more expensive'. And social services then were offering I think a certain amount of money and it was always we had to put a hundred and fifty, two hundred a month to get the better ones.

Stella, Daughter, Interview no. 1

In relation to selecting a nursing home the sense of *working in the dark* was a common experience. Most participants were charged with the responsibility of finding a home themselves and many did not know where to start. The majority were provided with nothing other than a list of homes, with no guidance on the criteria to use to help them compare homes. Two participants did not even have access to a list of homes and relied on listings in the telephone directory. In the absence of support and advice from health and social care services, the distinction between various types of home (elderly frail or elderly mentally ill, residential or nursing) remained a mystery. In those circumstances where some choice was possible there was often little option but to *'trail around'* homes in search of one that appeared acceptable. Furthermore most relatives didn't know what to look for in deciding which home would be appropriate. Doreen for example described how difficult it was to judge the suitability of a particular home in the absence of any indicators of quality:

"...the list he gave me - I didn't know which to start at. We looked at about eleven (homes). What I don't agree with in these places... it's the lack of any grading system on the homes. You didn't know what sort of place you were putting your relative in who you love. You don't know whose care you're putting them in to - that's appalling! I mean you can go in and everything looks fine...of

course it does! They're not going to do what they normally do. So where is the yardstick to measure these places by?"

Doreen, Daughter, Interview no. 2

Relatives were desperate for any kind of 'insider knowledge' to help them with their decision but found that social workers in particular were often reluctant to recommend individual homes. Personal recommendation, particularly from a health or social care professional was highly valued and often led to the selection of the home. However, more frequently relatives had to rely on less formal contacts. Where they were able to glean information about a particular home from friends, relatives and colleagues, this sense of *being in the know* was an important factor in decision-making.

Most relatives found it difficult to know what questions to ask on visiting a home. While they usually inquired about activities within the home, few asked about staffing levels. Furthermore very few of the relatives interviewed were aware that they could access the inspection reports prepared by the local registration unit and none had asked to see these. The invitation for the older person to spend a day at the nursing home prior to making a decision, an opportunity which could really contribute to the sense of *being in the know* was welcome but rare.

Arranging the financial aspects of the move was another area where many relatives felt they were *working in the dark*, and this was a major concern for more than half the participants interviewed. The system for funding long-term care is complex and was described by relatives as '*a nightmare*' and '*a minefield*'. Most participants did not know what benefits they were entitled to claim or how the nursing home fee would be calculated. For some this resulted in extreme anxiety over a long period of time:

"Reading this form it's still £117, it started off at £200 and something, I signed it but I still don't know whether this £117 is

going to be made up with her pension and the other bit. If I get a bill for £117 a week I'll just die...it's still not clear."

Edwin, Husband, Interview no. 14

"The form I had to fill in was 37 pages long."

Jack, Husband, Interview no. 31

"Nobody tells you what's what. You go to the homes and they say the fees are this. And you think goodness – three hundred and fifty pounds a week! But they don't say - this is how it works so you can afford it - you get so much from social services, so much from pension, so much from this and if there isn't enough you've got to find the money. So you've gone into homes and thought 'I've got to find this money'. So you think 'Well I wonder if another home will be any different'. Nobody tells you how much. And I think that's what it needs. Not only how much but how much do you get from social services and allowances and so on. You want somebody to sit down and say 'Have you got any pension? Put that down, put that down, add that up. You get so much from social services and you might have to pay about two pound a week.' Oh that's OK."

Mary, Daughter, Interview no. 10

Feeling supported / feeling unsupported Where relatives felt that they had received sensitive support from service providers, were kept well informed and had been encouraged to 'take their time' in making decisions, these aspects were much appreciated and seemed to make an important impact on experiences of care. This was apparent in John's description of the support he received from his social worker while deciding on a long-term care option for his parents following his mother' stroke:

“He knew exactly what I was on about, and I’m not just talking about when I spewed facts and figures at him. He knew what was going on in here (points to head), he knew what was going on in here (points to heart). He was totally sympathetic. He listened to what we wanted to do. He knew that at that time - initially we were looking at this twenty-four hour care business, he knew it was not what I wanted, he knew why we were looking at it, he was still prepared to go through it all and came up with the numbers and we could have had it, the twenty-four hour care, and he was not the slightest bit phased when I rang him and told him that we’d decided to go for the residential care. He’s been down to see my dad. A really, really nice bloke.

John, Son Interview no. 12

However, many participants felt that they lacked support for themselves during this period, particularly those who did not have close family members to turn to.

“I really, really_would have loved (original emphasis) somebody to talk to at that time and there was nobody in my situation to talk to - there were nursing staff on the ward but I really didn’t want to talk to them about it then - I wanted someone in my situation, and at that time there wasn’t anybody - not just for me.

Stella, Daughter, Interview no. 1

Such experiences contrasted sharply with those of a small number of participants who were either extremely confident themselves at dealing with such decisions, or received close support from social services personnel throughout this period. Feeling supported by highly trained people who knew what they were doing contributed to a sense of *working together* and enabled relatives to retain a sense of *being in control*.

Clearly however, most of the participants in this study had made decisions about long term care in less than ideal circumstances, with competing pressures and a lack of information. While the initial phase of decision-making was often a difficult period in many respects, subsequent adjustment following the move provided many more challenges.

‘Making the move’

The period immediately prior to, or following, the older person’s transfer to the home has been termed ‘making the move’. Again the dominant motivation for carers at this time was to try and ensure that they secured the best care for their relative. For most of the carers, and the older people, the nursing home was a strange environment, one with which they had little previous experience. Therefore, one of the primary tasks was to try and make it as familiar as possible both for the older person and the family carer(s), whilst at the same time establishing relationships with the staff and helping them to become familiar with the needs of the older person and of the carer(s). These three aspects were clearly inter-related and have been termed:

- ◆ ‘making it familiar’ - concerning family carers’ efforts to make the home familiar for the older person;
- ◆ ‘making them familiar’ - attempts to ensure that staff were familiar with the older person, and to a lesser extent the family carer themselves;
- ◆ ‘becoming familiar’ - describes family carers’ efforts to become familiar with the new environment and their new roles.

Once again the success, or otherwise, of relatives’ efforts in relation to the above can be understood in terms of the five factors which were used to explain the initial phases of the transition.

Being under pressure / no pressure In relation to the actual move to the care home, participants varied in the extent to which they had been able to plan the

move. Where the older person had moved in a crisis situation, obviously little forward planning was usually possible. However, with the luxury of more time, some participants went to significant lengths to ensure that the older person would feel at home. These efforts included arranging for items of furniture to be placed in the new room, preparing information about the older person, including photographs, which might be helpful to staff, decorating the room with memorabilia and photographs and ensuring that they could spend time with them helping them to settle in.

Whereas the move to the nursing home might be expected to alleviate some of the pressure on relatives to provide daily care, many participants continued to experience time pressures within their day to day lives. All the relatives interviewed continued to visit at least weekly and many, particularly spouses, visited daily. These visiting patterns continued to place demands on often busy schedules, particularly for working sons and daughters with families of their own. Many of the adult children described the stress which their continued support for their parent placed on their own marital relationship.

Working together / working apart A particular concern for all relatives at this time was to ensure that staff would quickly assimilate knowledge of the older person's condition and of their particular likes and dislikes. However, the extent to which they were encouraged to contribute to this process varied, with the majority being unaware of whether a detailed assessment of the older person's needs had taken place. In most cases, relatives were unaware of the existence of a care plan. Some participants acknowledged that their relative was sufficiently cognitively aware to be able to take part in an assessment without them being present, and consequently an assessment may have taken place and a care plan developed without their knowledge. Nonetheless this finding suggests that care home staff did not draw upon the knowledge and expertise of family care-givers in developing plans of care for these residents. In this context, relatives were left to their own initiative to improvise ways of ensuring that staff got to know the older person.

In some cases, participants' intentions to continue to be actively involved in the day to day care of their relative were thwarted by rigid and insensitive practices on the part of care staff. Several participants recalled how they were advised by care staff not to visit for a few days to allow the older person time to settle in. Most chose to ignore this advice but felt that this sent a message that they would no longer play such a significant role in the older person's life. The admission assessment provides an important opportunity to clarify roles and responsibilities and to make expectations explicit. However, most participants were not asked about the extent to which they would like to continue to contribute to their relative's care. On the contrary, as suggested above, some care home staff appeared to attempt to deny relatives the possibility of continuing to fulfil a function which they saw as part of their role, as Jan explained in relation to her uncle's care:

"And as I was telling you about his clothes – 'Oh we've got a lady that'll do this' - this sort of attitude. I've been and told them everything that they want to know, and I will buy his clothes. I object strongly to that lady telling me, you know, to that extent. If they had said to me, 'Well we've got a lady Mrs. P, that sees to the needs of clothing, and if you like then she will go and do the shopping for you' - now that's a different kettle of fish. But to turn round and say, 'and we've got someone to see to the clothes', it's a different attitude all together and I object to it strongly, I really do."

Jan, Niece, Interview no. 21

The language used by some care home staff: *'We'll take over now – you have a rest'*, while possibly well-meaning, implicitly suggested to participants that staff perceived they would have no further role to play in meeting the physical care needs of the older person. Once this initial pattern was established, it often proved difficult to make adjustments at a later date.

In the absence of a system of open and frank discussion, participants were forced to use more covert tactics to ensure that the home was becoming a familiar place to their relative. Most participants described a period following the move when they were particularly alert to the older person's mood and behaviour as a way of seeking signs that they were settling in and that the home would provide a suitable long-term environment. Checking whether their relative had been involved in any activities, asking about their dietary intake and appetite and observing the way in which care staff spoke to their relative were some of the indicators that were used. However, many felt unable to share these observations with staff, contributing to a sense that they were working alone in the best interests of the older person.

Feeling supported / feeling unsupported The day of the move was recalled in vivid detail by some participants, less so by others. The majority accompanied their relative to the home, or alternatively arrived shortly before or afterwards. Being met at the door and shown to their room, being introduced to other residents and being made to feel welcome with a cup of tea were all important in reassuring relatives that they had made the right choice. These aspects were generally managed positively by care home staff. Nonetheless, the move itself was a traumatic experience for most participants, many of whom described overwhelming feelings of guilt and loss:

"The matron and the other lady we know greeted us - that was quite nice. Mum was taken to her room...she was quite upset and I did nothing but cry. Just the thought of having to leave her there. One of the sisters tried to comfort me, she was very good"

Elsie, Daughter, Interview no. 8

For some participants such feelings contributed to a sense of 'riding the rollercoaster' as they alternated between feelings of reassurance that their relative would now receive appropriate care and despair that they were no longer able to provide this care. For many participants, the move to the nursing home signalled a

further change in an already changed relationship. For adult children, a pattern of role reversal, with the older person becoming increasingly dependent on them, was interrupted by the transition to nursing home care. Some responsibilities were handed over to care staff with some retained, particularly in relation to financial matters. The perceived handing over of responsibility was a traumatic experience but the way the situation was approached by staff made a significant difference:

“They were lovely. And so that made me feel better. Because, it is, an emotional experience. Because I’ve been responsible for him for the last six years and to suddenly, let go, and hand him over to somebody else, and think oh, you know I hope it’s going to be all right. I did feel quite emotional about it. And I shed quite a few tears over it. But you know they’ve all been so lovely. And that’s helped. I feel now some of the staff are more like a friend.”

Joan, Daughter, Interview no. 18

This kind of experience contrasted sharply with those of other participants who found that their feelings were never acknowledged:

“Yes, well I think there’s a lot maybe, either at the hospital or at the home that someone could have said, you know – ‘How are you feeling about this? How is it affecting you? Are you coming to terms with it?’ Where I just got on and did it, you know, I didn’t have time really to think.”

James, Son, Interview no. 17

For co-resident caregivers, the biggest adjustment was in suddenly being relieved of the responsibility for meeting the physical needs of their relative. However, this often left a void, and initially at least, participants felt exhausted after years of day-to-day caregiving. Feeling the need to visit every day, or sometimes twice a day,

meant that spouses frequently perceived little benefit to their own physical well-being from their partner's move into the nursing home. In between visits to the home, the feelings of loss and loneliness were acute. However, in only one case did a relative feel that their own needs had been systematically assessed by staff: this lady was invited to complete a questionnaire on her mother's admission to the home.

SD ("And so the home where she is now, have they been quite receptive to your wish to be involved?")

"Yes, yes they have. Yes, and I made that clear from day one. There was a questionnaire and they said 'How much do you want to be involved. You know would you want to know if you were away, if anything happened to your mum?' I said 'Oh I would! They also asked me about my own feelings about my mum moving in, was I okay about it.'"

Kate, Daughter, Interview no. 20

Giving up their relative's home involved a further adjustment for non-resident carers. In some cases this involved saying goodbye to a house and possessions which they had known since childhood. Disposing of their relative's assets also held the potential for family conflict resulting in further distress. The sharp adjustment to changes in their relationships and lifestyle following their relative's relocation had the potential to create powerful emotions of guilt and anxiety which many participants found difficult to deal with. The key to a successful transition appeared to be the availability of a confidant, often a social worker but occasionally a friend or relative, who could support, listen and offer advice and comfort. For a small minority of relatives, staff at the nursing home performed this function. The important ingredient appeared to be the ability to empathise. In the absence of such support, relatives often felt alone in the experience.

Most participants did not anticipate that staff would be interested in their own needs. However, in the absence of any assessment, many relatives were left to work through their feelings and emotions at this time without support. It was natural that participants should have reflected on the decisions they (and in some cases their relative(s)) had made. For some, such reflection was painful and caused them to think that perhaps the decision had not been the right one after all.

“If I could turn the clock back, I think that I might have gone down a different avenue. And I would have insisted that I get more help in the community, to perhaps keep her at home for a few more months. I could perhaps have said that she might even be with me now. Then perhaps I could have let go when she really got bad. But I can’t turn the clock back. So I’ve got to accept what it is at this moment in time.”

Ron, Husband, Interview no. 15

Others were reassured about the placement in spite of initial misgivings:

“She often says ‘They were sitting in my room before lunch, having a break.’ So I think they sit and chat to her and tell her all their life histories, which she quite enjoys. So the more it goes on, the more happy I am she’s there. Because she’s seeing far more people than she would have staying with me.”

Alice, Daughter, Interview no. 22.

It is possible that greater contact and discussion with staff may have enabled some relatives to perceive such benefits more clearly.

Working in the dark / Being in the know An opportunity to clarify what the home could be expected to provide in terms of care and support was also often missed at the admission stage with the result that relatives again felt that they were

working in the dark. For example a number of participants fully expected that their relative would receive rehabilitative services which were then not forthcoming, resulting in disillusionment and disappointment. Most participants were aware that they could visit the home at any time and this was appreciated. However, what they might expect during the course of their visits was often left to the vagaries of individual members of staff, as one spouse revealed:

SD ("Are you ever able to have a meal there with her?")

"Well I used to have. There you used to be, it just depends who's on. They'd say 'Would you like a dinner Jim?' and I'd say 'Yes please'. But they never asked me for ages, about twelve months since I had one. I'm not bothered."

Jim, Husband, Interview no. 25.

On the whole, participants had not been provided with a great deal of information to help them to plan for the future. Most did not know what to expect in relation to their relative's likely deterioration and a few continued to harbour hope of a miraculous recovery. A small minority of participants continued to consider the possibility of bringing their relative home to live with them, particularly where they were unhappy with the quality of care at the nursing home.

Being in control / losing control A relative absence of control is apparent in many of the above accounts and another area where many relatives felt they were not in control became apparent when the home was found to be unsuitable. Most participants recalled a review meeting within about a month of the initial relocation at which an agreement was generally reached to make the placement permanent. Following this meeting regular social work support was usually withdrawn and most participants suggested that they would find it difficult to know who to contact outside of the home if they were unhappy with the placement.

Three participants within the sample had helped their relative to change homes following initial placement, one because she and her mother were both unhappy with standards of care, and two because the first home was no longer able to meet the older person's needs. However, most relatives perceived that changing homes would be almost impossible, even if they were unhappy about standards of care. This was partly because publicly funded placements were considered to be virtually irreversible but also because relatives perceived that relocation would be too unsettling and stressful for the older person. There was also a feeling that another home may not be any better.

While it was generally clear that placements were initially for a trial period, what was less clear was the fact that this meant that staff could decide that the older person was not suitable for the home. May, for example (Interview No. 4), was told that the home where her mother had moved two weeks previously could not actually meet her needs and she would have to find an alternative placement. This was very distressing for both her and her mother. Where relatives were asked to find an alternative placement, it was difficult not to see this as a rejection of the older person, and to some extent themselves. It also involved a further search for a more suitable placement.

For most participants however, their relative remained at the home into which they had initially moved. Once a placement had been agreed as permanent and the initial adjustment had occurred, part of the on-going process for relatives was to create and maintain a role within the home.

'Making it Better'

"I'm getting there. I know he's got to be there. It's for the best. But with, with me going, making it better, making his world better."

Jean, Wife, Interview no. 35

Of the three phases of the move to the nursing home, there is no doubt that participants devoted most time and attention to the third phase, that of 'making it better'. This not only reflects the fact that most relatives were still engaged in trying to ensure that the older person received the care that they needed, but also gives an indication of the importance they attach to their on-going relationship. As the above quote illustrates 'making it better' is primarily about making the 'world' of the older person better. In other words, it is about trying to ensure 'best care'. However, as will be seen, both later in this chapter, and in chapter 5, relatives also had the potential to improve the experiences of other residents and of staff. In other words, they were able to contribute to the community of the care home, thereby potentially 'making it better'.

Relatives saw their contribution as an important component of ensuring best care for the older person. This involved them both in making a personal contribution to care and in monitoring the care practices of others. The personal contribution to care involved relatives both in *maintaining continuity* and, as previously mentioned, *contributing to community*. A third element in 'making it better' involved a less overt contribution to care in the form of monitoring of standards and this has been termed *keeping an eye*.

As will be seen in the next chapter the notion of 'community' is a key one and, on the basis of the case study data, a number of differing types of community could be identified, which either facilitate or inhibit relatives' efforts to ensure best care. These were also alluded to within the interviews with relatives as will be discussed later. However, first the relatives' contribution to care will be considered in more detail.

Maintaining continuity Maintaining continuity is based primarily on the relative's intimate knowledge of the older person. This personal knowledge, in combination with efforts aimed at the continuation of the relationship with the older person, represent the relative's unique contribution to enhancing quality of life for the older person within the new home. However, this is not simply altruistic as most relatives continued to experience strong feelings of love and

affection towards the older person and perceived an enormous benefit to themselves from their continued involvement. Despite this continuing bond of affection, experiences of visiting were mixed with a small minority of relatives describing their visits as '*a duty*' or '*a chore*'. Some related feelings of heightened anxiety before a visit, particularly where the relative was cognitively impaired, wondering what condition their relative would be in and how they would respond. Others, particularly spouses, described how much they enjoyed their visits which had become a focal part of their day.

Participants described numerous ways in which they strove to maintain continuity for their relative. They talked of '*doing what we've always done*', wherever possible, replicating routines and practices which they used to engage in when the older person lived at home, for example watching the football results together or doing the older person's hair. They also described their continuing efforts to ensure that members of staff were aware of the older person's identity, likes and dislikes. James described what he did on visits to his mother who had been admitted to a nursing home three weeks previously:

SD ("What sort of things do you do when you go there?")

"Well it's mainly discussing things, sometimes it might be helping her with feeding, if she can't manage to feed herself. Or it might be pointing out what a particular piece of food is, if she can't see it properly. It might be repeating something that a care assistant has said to her, because she can't hear very well."

SD ("Just sort of general every day things really?")

"Yeah."

SD ("Being there for her?")

“Yes. And giving her emotional support, someone to talk to who she can get on with and understand. Even trying to, put her words together what she’s not able to communicate, and fitting in the words and trying to get her sentences together and helping to say what she really means. And sometimes passing on messages.”

SD (“For the staff, or? ...”)

“Erm, well from the staff to members of family, to her friends she’s not seen, to the people that used to come and visit her.”

James, Son, Interview no.17

In this sense, James felt that he acted as a link to the outside world, but also tried to assist his mother to become part of the new community into which she had moved.

Contributing to community Most participants perceived that they had a responsibility to contribute to the life of the home in addition to providing support for their own relative. For some relatives, the nursing home had become a community of which they felt a part:

“We do try to help out when we visit. I’ve knitted about twelve blankets for them and we often take residents back to their rooms. Sometimes they say ‘Oh we’re glad to see you, you can give the teas out!’ I don’t mind this and I enjoy being with them. You can have a laugh with some of them.”

Elsie, Daughter, Interview no. 8

An important aspect of this wider responsibility involved developing relationships with other residents, particularly those who had few close family members themselves:

“I have a lot of contact with the other patients because I like them. And er, I’ve got to know them all by name, I mean, my mother’s neighbours, Ellen Partridge, she’s ninety-two. Little lady Alice, she’s ninety-seven. Elsie, she speaks French, and I say to her, you know ‘Bonjour’, and she, oh she’s so pleased that somebody can speak a little bit of French, and she responds to you in French.”

Gerald, Son Interview no. 16

Some participants expressed surprise that staff didn’t do more to encourage relationships between residents and saw themselves as an important link in this respect:

“...but I do think they could encourage the ones who talk to sit together and they don’t always do that. If they did that and a member of staff sat with them they could talk about anything. He has a newspaper – I always take the Sheffield Star, so he has something to talk about.”

Jane, Daughter, Interview no. 5

Most participants obviously felt that they also had a responsibility to support the staff in caring for their relative:

“It would be easy to say not go, but then if I don’t go, she seems to get more and more difficult and staff have more problems with her.”

Angela, Daughter, Interview no. 27

By contributing their ideas, resources and time, some relatives were aware that they had the potential to enrich the lives of other residents and staff, as well as

their own family member. However, it was also apparent that many relatives had received little encouragement to recognise or build upon this potential.

Keeping an eye In addition to their own personal contribution to the older person's care, participants perceived an important role in monitoring the standards of care for their relative and providing feedback to staff. On the whole, participants were very clear about the standards of care which they would like their relative to receive. However, these expectations were rarely met in full. A number of themes could be discerned in accounts of care practices within the home, suggesting that 'best care' reflects specific criteria. These are summarised in Table 4.2. The interview data include examples of experiences representing both ends of each continuum and it was often these criteria that relatives engaged, either implicitly or explicitly, in informing their judgements of best care.

These perceptions of care practices within the home contributed significantly to relatives' personal experiences of this phase of the move. Once again, these were influenced by the five continua which have provided a framework for the analysis thus far. These will now be considered in turn, integrating relatives' experiences of their own contribution with their experiences of care under each heading. What begins to emerge is a suggestion that these five continua may also be important in defining the experiences of staff working within homes, in turn creating a specific type of 'community' within a home – a point which will be considered in more detail in Chapter 5. But first, the experiences of relatives will be described in more detail.

Working together / working apart The most important factor in determining relatives' experiences during this phase of the move appeared to be the extent to which they were able to work collaboratively with nursing home staff to ensure best care for the older person. Furthermore, the experience of a mutual or reciprocal relationship with staff was essential to perceptions of high quality care for relatives. The willingness of staff to work collaboratively was manifest in a number of care practices, for example involving relatives in care-planning and decision-making. Informality in relationships - being encouraged to call staff by

Table 4.2 Care characteristics representing dimensions of best care from the relatives' perspective

BEST CARE	WORST CARE
Staff are friendly	Staff are detached and impersonal
Staff know the older person and recognise their needs	Staff don't know the older person and fail to recognise their needs
Staff have the right approach	Staff don't know how to talk to older people
Senior staff are visible and accessible	Senior staff are rarely seen
Staff make suggestions about care and treatment	Nothing new happens unless initiated by relatives
Staff are accessible and respond rapidly to relatives' concerns and follow through with action	Staff are rarely seen and relatives' concerns and requests are ignored
There is flexibility in day to day routines to ensure that residents' needs are met	Daily routines ignore needs of individual residents
Staff take time to talk	Staff are too busy to talk
Residents have named carers who care for them regularly	Different staff are allocated all the time
Staff show that they care	Staff are rude or indifferent
Staff pass on information to relatives spontaneously	Relatives have to ask staff for information
Care is reviewed regularly and planned to meet the resident's needs	Care is frequently inappropriate and there is little evidence of systematic care planning and review
Staff recognise relative's expertise and involve them in decision-making	Staff take over care from relative without negotiation
Staff show appreciation for the relative's contribution to care	Relative's contribution is not acknowledged or relatives' are seen as 'interfering'.
Staff attend to small details of care which make a difference	Details of care are missed or neglected

their Christian names, having a laugh and a joke, feeling that the staff would make time for them, all contributed to a sense that staff valued relatives' input. Frequently however, more adversarial relationships were described with few attempts on the part of staff to involve relatives as equal partners. Many participants perceived reluctance on the part of nursing home staff to see them as partners in care and to recognise their expertise:

"...because they think they're the trained ones with all the answers.... You're not trained - the fact that you've been doing it doesn't count. You're not trained."

Mary, Daughter, Interview no. 10

However, such failure to draw upon relatives' expertise could have important consequences for the older person. Edwin for example described what happened when nursing staff chose to ignore his advice about his wife's medication:

"And they once gave her...a sedative. Now Edith (wife) is very peculiar regarding pain killers and sedatives, she has a very low, I don't know the correct expression, but I would say a low tolerance level. And if you give her er, er...something like, co-codamol or codeine or diazepam or distalgesic tablets, or any of the stronger things, dihydrocodeine, if she has any of those she'll pass out. She can only take paracetamol and aspirin. So when they gave her a sedative to quieten her down at night, when they gave her what the doctor recommended at (Nursing home A), the doctor prescribed it, they gave her a dose and she was out for two days. That sort of thing you see. So I sort of remonstrated about that, just said 'Well I did warn you about only giving her a very tiny dose of anything'."

Edwin, Husband, Interview no. 14

The most positive perceptions of care were associated with a sense of shared understanding of the aims of care for the older person. This was often the outcome when staff, particularly qualified staff, made time to talk with relatives on a regular basis. Regular reviews of the older person's care needs involving the older person and their family were also much appreciated. Where staff and relatives had clearly defined roles and responsibilities in relation to the older person and where these had been negotiated and agreed, relatives were usually highly satisfied with care. Staff could also enhance the experience of visiting by working together with relatives, for example offering refreshments, joining in when conversation was obviously flagging and arranging furniture so that visitors had somewhere to sit:

"...and they are very sensible people there, they never sit two people together. They always leave a chair in between so relatives can walk straight in and sit down. And the carers, there's always somebody there, one carer can always move along if someone hasn't been spoken to for a bit, and can walk along and have a few words with them, and that is what I like. And there is always, I never have to get a chair. There's always one there. And there's always one there for the carer, which is a very good idea."

Edwin, Husband, Interview no. 14

However, often relatives were left to their own devices and had to manage their visits with little input from staff. Some found it easier to visit with another relative or friend, some read the newspaper with their relative or watched television or listened to music together. Some involved themselves in practical tasks such as sorting out clothing, tidying their relative's room and hair-dressing. Many saw an important role in taking their relative out of the nursing home whenever possible; however, again this was dependent to some extent on their own degree of frailty and on the resident's physical abilities. Very few received support from staff in this respect but where such support was forthcoming, it was greatly appreciated:

“During the summer, Des - everybody thinks Des's marvellous, some of the old women say they are going to marry Des, and another woman shouts ‘You'll have to get in the queue’. Anyway Des said, ‘You know, if you want to take Peter for a walk any time, I'll go with you, when I finish at two.’ I says ‘Well I don't want you to give me your time out of your working.’ He says ‘There's no problem, no problem.’ No gifts or anything like that you see. So we arranged it for one morning, when he finished at two. And he said ‘Where do you want to go?’ He said ‘You don't live far do you?’ No, but I said ‘It's up hill.’ So he said ‘No problem.’ So we brought him up here you see, Des wheeled him in his wheelchair. Well unfortunately the wheelchair was too wide to get in our front door, in the porch. And we had to kind of manhandle him, and get him in the chair there. But he'd got his eyes closed, and he didn't know where he was. And that helped me too because I knew he wasn't missing it at all. And so he sat there, he hardly opened his eyes, he didn't say anything. And Des spoke to him and he kind of laughs, and we had a cup of tea. But it made me realise that it wouldn't be any better for him really to be here. And so, it was good of Des. And then we went for a walk round the block and he took us back. And he does this a lot.”

Mabel, Wife, Interview no. 23

The extent to which relatives perceived care staff to be prepared and equipped to care for their relative influenced expectations that they would be able to work together to provide ‘best care’. Most relatives differentiated between care workers, perceiving some as good at their job and others as not so good. This was perceived as the product of a number of factors, including training, leadership and pay. However, there was also a less definable component which seemed to reflect the careworker's underlying motivation to work in this setting. For example, relatives described care workers who were ‘natural’ and ‘born to it’.

The importance of adequate training for staff in securing positive care experiences was highlighted regularly. Most relatives were unaware what training, if any, care assistants had received, but a consistent theme was concern about the way some care assistants spoke to residents, particularly a tendency to infantilise older people in their care. There was a commonly held perception that care work is low status and that some carers 'end up' in this line of work because they are unable to work elsewhere. However, relatives also spoke in glowing terms about particular nurses and carers who were dedicated and committed to the job.

Some relatives perceived that staff, including qualified staff, lacked detailed knowledge in relation to specific conditions affecting their relative for example, arthritis, diabetes and blindness.

"I think there's a tendency to be a bit too 'gung ho' about, trying to make things as normal as possible, perhaps to the detriment of her medical condition. So I've had to keep a very very close eye on feet and things. And what surprises me is that young carers don't know about how to look after diabetic feet. So I took in some instructions. I even said to one 'There's a book there, you should have a look at it'."

Molly, Daughter, Interview. no. 30

Again there was a general lack of awareness of the qualifications held by qualified staff and the different roles they played within the organisation.

Continuity of carers, particularly through the use of carer allocation systems, had the potential to ensure that staff were familiar with the needs of residents and the extent to which relatives wished to be involved in meeting care needs. Twelve-hour shifts where these were in operation also provided continuity of carers. However, more frequently, high staff turnover was cited as a factor contributing to dissatisfaction with standards of care.

“It depends on the carers who are on; some of them are very caring, others are there for the day. And I think the worst case is the - what I call the agency nurses, you know they don’t... - it’s impossible for them in a ten minute briefing to take on that patient, to understand the medication that that person’s on.”

Gerald, Son, Interview no.16

Relatives also described how key-workers were sometimes changed without consultation, often when close relationships had formed.

Participants expected that staff within the home would use their initiative to develop a plan of care and introduce them to activities which would meet the needs of their relative. Some were impressed that care staff had recognised the need to involve other agencies such as a dentist, optician or chiropodist and had arranged this spontaneously. Others expressed gratitude that staff had recognised their own needs and had gone out of their way to make them feel at home as Molly recounted:

“One night I went in, I had some Irish visitors. We went in the little smoking room, because one of them smoked. We sat there, we started to sing. And John (home manager) came in with a tray of wine. And I thought that was a lovely, lovely touch. And we all had a glass of wine each. He saw this little party developing and he thought ‘I’ll enhance it’. So that, that was lovely and there was Rachel, who loved it. And Greta*, and Eileen*, and they were all involved.”*

*** residents**

Molly, Daughter, Interview no. 30

Staff could also demonstrate initiative in their willingness to be flexible in relation to the normal routines within the home if this meant that an older person’s needs could better be met. However, more frequently, the routine was pervasive, and

while some participants recognised the demands on staff to ‘get through the work’, the needs of their own relative were, understandably, their prime concern.

“Mum likes to be in bed at about eight o’clock although I think bedtimes are to suit the nursing staff. They have their routines and when I asked why they leave my mother until last they said ‘Well we start from the other end’, and I say well why can’t you start this end? Sometimes I feel I’m always complaining.”

Maria, Daughter, Interview no. 9

A final aspect which contributed to some relatives’ perceptions that they alone were working in the best interests of the older person arose directly from the location of much continuing care provision within the private sector. The incentive for home owners to maximise their profits was felt by several participants to conflict with their own intentions to provide the best possible care for their relative. Again, a sense of isolation was apparent here, with many relatives feeling that home owners and staff were motivated by very different considerations from themselves.

Working in the dark / Being in the know A consequence of many of the factors discussed above was that relatives frequently felt that they lacked guidance from staff on the most appropriate way for them to continue their relationship with the older person and make the optimum contribution to their care. In particular, they would have appreciated suggestions and ideas on how to manage visits. In the absence of such guidance, most participants had to work out for themselves what the most appropriate pattern of visiting was for them. A number of strategies for successful visiting were described, with ‘*having a routine*’ for the visit mentioned recurrently. Again, this was easier for relatives of residents without a significant degree of cognitive impairment: where the resident was confused and their behaviour unpredictable, having a structure for the visit was not always possible.

Some relatives were anticipating the possibility of reducing the frequency of their visits in recognition of the impact which their regular pattern of visiting was having on their own life. A few felt driven to continue to make daily visits in spite of feeling that this was probably benefiting no-one. Conversely, as previously mentioned, older participants, particularly spouses, were committed to visiting daily and described how this has had become a major part of their reason for living. This raises questions about their plans and preparation for the future when visiting the home is no longer a part of their daily routine. However, only one participant described how staff at the home had attempted to prepare him for the death of his wife, sitting down with him and describing the likely course of her illness. This was much appreciated by the participant concerned. Unfortunately, such emotive matters were not always handled so sensitively. One son for example, described his distress at being asked quite starkly about preferred funeral arrangements for his father on the day of admission to the home. Certainly the data suggest that most participants had received little help or support to anticipate the future decline or death of their relative. Again they felt that they were in this alone and *working in the dark*.

Being in control / lacking control Where relatives were able to work together with staff and were kept well informed about their resident's progress and care, they were able to retain a sense of control over events. More commonly however, they felt that they were unable to exert much influence on care practices within the home. Where relatives had asked for aspects of care to be modified and this hadn't been achieved, a failure in staff-to staff-communication was often felt to be at fault, commonly linked with a lack of continuity in staffing arrangements. Problems with written documentation were also highlighted:

"I rang up last week on one of the days that I wasn't able to visit, I wanted to find out if she had got her new glasses yet. I was talking to a lad on the phone and he said he would just check the notes.... Apparently there was nothing in the notes about her glasses but he did say that she's got this MRSA. I didn't know anything about this - I was very annoyed. I then asked the carers why they weren't

wearing gloves. The sister told me that it was nothing to worry about - we all have it!"

Elsie, Daughter, Interview no. 8

Such failures in communication did little to reassure participants that their relative was in 'safe hands'.

Relatives were happiest when they felt that staff shared their sense of responsibility for the older person. Staff showing that they cared, noticing and reporting changes in a resident's condition, demonstrating respect for the older person's personal space and possessions, were all subtle indicators that the staff took personal responsibility for the care provided and that the older person's opinion and those of their relatives were important, in turn contributing to a maintained sense of control. However, in some homes a culture of failure to take responsibility seemed to have developed, resulting in feelings of frustration and impotence for relatives:

"When I complain about things it's always somebody else's fault. Then her glasses went missing. The matron turned round and said 'They have probably been thrown in the bin.' I told them that she needs glasses so could they arrange for an optician. Then the matron said 'Well you will have to pay', even though they had actually lost the glasses. I wasn't very happy. Nothing like insurance has been mentioned. When her (gold) chain went missing, we were told it was probably one of the carers, so we asked for it to be reported to the police, but when we asked for the incident number later on the matron said she didn't have one. I would think that the home would have it's own insurance, but

nobody has ever said anything about that to me."

Elsie, Daughter, Interview no. 8

In part such data speak to the importance of relatives feeling that there is someone in the home who has overall responsibility and to whom they can turn when they have worries and concerns. Regular access to senior staff appeared to contribute to relatives' perceptions that their views would be taken seriously and that staff would be managed effectively:

"In (Nursing Home A) you never saw the matron. The matron had a holy of holies, it was down in hell, it was downstairs. I only saw the matron once when she interviewed me, which was fair enough, very nice person, I've no doubt very capable. But she doesn't seem to be out and amongst it. Now this chappy at (Nursing Home B), Sam, he's out and about, saying hello to people and this kind of thing. Whether he's got a better deputy or not I don't know. You just don't know. You can only work with the staff you've got can't you. So I just don't know, but I always felt the matron at (Nursing Home A) was remote. And that she hadn't got a hands on approach, and you need that if you're in a whole team, unless you're going to play God in the mountains, you're not going to get very far, you're going to be relying on somebody else."

Edwin, Husband, Interview no. 14

Under pressure / no pressure In the context of providing continuing support to their relative, pressure was most frequently experienced in relation to trying to balance time spent at the nursing home with time spent meeting other responsibilities. As mentioned previously, all the relatives interviewed continued to visit at least weekly and many, particularly spouses, visited daily.

Routines within the nursing home also exerted a subtle form of pressure; for example being encouraged not to visit at meal-times meant that some relatives had to plan the timing of their visits carefully. However, a small number of participants described a new-found sense of freedom following the move and in particular were enjoying being able to go out when they wished. There were also advantages for some in a different pattern of visiting involving different activities and this actually reduced some of the pressure and enhanced their relationship with the older person:

“One of the good things about my mum being in the home is that the time we spend with her now is quality time, because we don’t have to do all the other jobs we were doing for her before, like washing and cleaning. Now we can just be with her and talk to her.”

Elsie, Daughter, Interview no. 8

Feeling supported / feeling unsupported The extent to which relatives felt supported by nursing home staff varied considerably and again this was largely dependent on opportunities to spend time with staff and talk with them. For some relatives, it had never occurred to them that the staff might be interested in their own needs. However, others lamented the fact that they had no-one to discuss their feelings with. The fact that many participants expressed on-going feelings of guilt and distress in relation to the move suggests that any such support would be justified.

Many participants expressed concern about the likely deterioration of their relative in the future and some were concerned about whether they would be able to continue to finance the placement. Some relatives expressed anxiety about their future ability to continue to provide on-going support to their relative but hadn’t felt able to discuss this with staff:

“The only worrying thing for me is I want to keep myself in decent shape. The main fact of that is if I keep myself in decent shape then I’m the mainstay for Daisy as well. And so I want to be able to help her and visit her, and keep that up as well. I don’t care what happens around here, if the garden deteriorates, tough, if the greenhouse is not attended to then hard lines. My main aim in life is Daisy.”

Ron, Husband, Interview no.15

A small minority of participants, mostly spouses, talked about their plans for the future within the interview, envisaging a time after their relative has died. However, for most relatives this appeared to be too painful to contemplate. Certainly, few appeared to have had an opportunity to discuss their plans for the future with nursing home staff.

Staff experiences

As well as providing a vivid insight into relatives’ ongoing experiences of continuing to play a role in the life of an older person admitted to a care home, these accounts begin to provide some indications of the factors which shape the experience of nursing home care for older people, for relatives and for staff. In particular, relatives seemed to have a keen awareness of the factors which contributed to staff members’ abilities to provide a high standard of care, or conversely, acted as constraints on the achievement of ‘best care’. On closer analysis it emerged that these factors mirrored the continua which described relatives experiences. For example, during the interviews (and concurrently within the case studies) it became apparent that when staff felt under less pressure, were knowledgeable, felt supported, in control and worked in partnership, then relatives were far more likely to be able to ‘make it better’. The main factors which relatives highlighted as contributing to staff experiences are summarised in Table 4.3. These will be explored in more detail in Chapter 6. However, in the context of the findings of interviews with relatives, the implication is that relatives are

Table 4.3 Relative perceptions of staff experiences in care homes which impact upon their ability to achieve 'best care'.

STAFF EXPERIENCES	Factors contributing to this
Being in the know	Adequate training and preparation resulting in appropriate levels of knowledge and skill for the job Consistent staff allocation so that carers are familiar with residents' needs Regular review of residents needs
↑ ↓	
Working in the dark	Lack of training and preparation for role Staff overwhelmed by complexity of resident needs No consistency in staff allocation so that staff are not fully aware of resident needs Heavy dependence on agency staff Poor communication between staff
No pressure	Adequate staff of appropriate grades Flexibility in relation to routines
↑ ↓	
Feeling under pressure	Staff shortages Rigid routines so that staff are battling to 'get the work done' Difficult and demanding residents and relatives
Being in control	Roles and responsibilities are clear Named nurses and carers have designated responsibility for the care of individual residents
↑ ↓	
Lacking control	Roles and responsibilities are unclear Staff feel they don't have the resources to change anything
Working together	Effective leadership and role modelling from senior staff Staff get on well with each other
↑ ↓	
Working apart	Little direction and leadership from senior staff 'Bitching' and hostility between members of staff
Feeling supported	Relatives show appreciation of staff Relatives and residents consider staff needs
↑ ↓	
Feeling unsupported	Low levels of pay and benefits Work seen as low status

often well aware of the various constraints under which many staff in care homes are working. Furthermore, many go out of their way to make allowances for what they perceive as less than 'best care' in recognition of these constraints.

'Making it better': acting to improve care

Not surprisingly, the relationship between expectations of care and care received was a key element in determining the extent to which relatives were happy with the placement. When care fell short of the standard which a relative expected, participants described a range of strategies for coping. Quite often this involved attempts to clarify the situation by asking questions. There was evidence for example of participants attempting to be fair to the staff by making sure that any judgements about the quality of care were based on accurate information:

"All the way through with my mum's caring, if she's not given a lot of attention she finds fault. So you have to sort out if it's what I call good attention which means independence learning, or you know you having to sort that one out - is it a valid argument or shall I let it slide? It is a bit like having a child - you send the child to school and you get feedback from the child about what the teachers are doing. I wouldn't naturally take my mum's side. I would delve into it - 'How did they say it? How did they pick it up? Why did they do it?' and think - no it's nothing. Like she might say 'Marie was a bit brisk this morning - wanting me off the toilet quick'. And I thought well poor Marie, might have had a bad night, might have had a baby, husband not talking - we're all human aren't we. So you just dismiss it don't you."

Jan, Daughter, Interview no. 7.

Some described their efforts to modify care practices by sharing their own views or by making suggestions, in an attempt to share their own expertise with staff.

For some participants this extended to *'showing them how to do it'* or role modelling the care which they felt to be appropriate.

A small minority of participants felt able to voice their concerns about standards of care, occasionally going to the lengths of making a formal complaint or even issuing an ultimatum when a problem remained unresolved. However, more commonly participants were concerned that voicing their dissatisfaction might jeopardise relationships with staff and even compromise the care that their relative received. In these circumstances they felt they had no option but to *'keep quiet'* and *'let it go'*. In part, these judgements reflected the staff's response to earlier comments and suggestions: where previous responses to voiced concerns had been sympathetic, relatives were more likely to feel they could raise issues subsequently. However, some relatives were so constrained by their own personal situations that they were forced to set new limits for what they perceived as *'acceptable care'*. John, talking about his parents said:

"They're together, they are looked after, they're warm and they're fed and there's somebody there twenty-four hours a day if they need medical care. Acknowledging the fact that we're here and we've got a family and we've got our lives to live, they're not here. You couldn't want for anything more than that. Now because you've got that situation – and even now we're still experimenting with patterns of visiting and trying to do the things we have to do like running the house, like decorating, we have difficulty in fitting in the things we have to do - and I'm not talking about going out, I'm talking about the things we have to do. We're struggling with our own lives and work and they are actually being looked after and to actually go somewhere and start beating your fists on somebody's desk and starting it all up again..."

John, Son, Interview no. 12

The negotiating strategies described above, and the staffs' responses to them shaped relatives experiences, particularly with regard to the relationships that they were able to develop with staff over time. Four types of relationship were discerned:

- ◆ partnership care ('working together');
- ◆ substitutive care ('getting on with it');
- ◆ submissive care ('putting up with it');
- ◆ confrontational care ('battling it out').

Partnership care - 'Working together' In the context of reciprocal relationships, with clearly established responsibilities and with staff recognising a relative's need to contribute to and monitor care, problems were normally rapidly resolved. Ron for example, felt that he had been able to establish this kind of collaborative relationship with the manager of his wife's nursing home, clearly illustrated in the following comment:

"There's only one thing I've been a bit concerned with, and that is she doesn't seem to be awake at all at the moment. I'll have to talk to Steve about it. I think she needs to have the medication reduced. She's spending too much time asleep. Steve will see to that and the doctor or the nurse will sort that out. Because he said quite openly, anything or any problems you want to talk about, do talk. So I'm quite happy."

Ron, Husband, Interview no. 15

Relatives perceived many benefits to a collaborative approach, in particular that the resultant combination of skills and knowledge could ensure that the older

person's needs were comprehensively met. This type of relationship enabled them to retain a sense of control - a sense that they could influence the care that their relative would receive. They also felt reassured that staff would contact them at any time if the need arose. An important aspect of this particular outcome was the sense that the staff really cared about their relative and also about the participant's own needs. There was also a recognition that achieving effective collaboration was not always easy and required honesty and compromise on both sides, as Kate explained:

“But you see I like them to address things with me as well. For example recently they asked me if I could provide her with a dress. And I'd provided mum with a dress that I thought would be appropriate, but it was the right length for her and it was very smart, but it's the way she sits, it was compromising her dignity. And they told me, so I said 'If you have any criticisms will you please let me know. I shan't be offended.' So it does work both ways.”

Kate, Daughter, Interview no. 20

Substitutive care - 'Getting on with it' Where relatives perceived gaps and deficiencies in care, one alternative was to attempt to fill these gaps themselves. This outcome often resulted when participants had attempted to role model 'best care' but this had not been followed through by staff. Jean for example described how she ensured that her husband was able to rest every afternoon and her concerns that, in her absence, this would not happen:

“Well I feel, it's shared care, and I'm caring for him when I get there, to coming away. And they realise this. Well I know they realise it. When, after Christmas, I started putting him on the bed, after he'd had his lunch, and a care worker came in and she said 'What have you done to him?' I said 'What do you mean?' She meant how have I got him on the bed? How have I got him lying

down? Well they had said they can't. Because he wouldn't stay for them. He would get up you see, and wander. Now I know he would. But once he's fallen asleep, he would stay asleep for a little while. He would stay asleep. And they said 'I wonder if we could', but they never have tried. So I go. He has a rest and, it stops him walking. It stops him wandering. I mean he's got low blood pressure. And you need to walk for exercise but I know, he'll be walking now. He'll be walking."

Jean, Wife, Interview no. 35

Submissive care - 'Putting up with it' This type of relationship seemed most likely to develop when staff at the nursing home attempted to take control of the older person's care and relatives felt unable to challenge this. Many relatives who perceived deficiencies in care found it difficult to raise this with the staff for fear of causing problems in their relationships with them. Some described fear of reprisals:

"They had put my mother next to a lady with Alzheimers. I was so worried about it all and I didn't want to upset anybody for them to take it out on my mother, because you do hear about these things. I felt that my mother was certainly being hit by this lady."

May, Daughter, Interview no. 4

Where relatives responded passively, fitting in with the routines and expectations of the home, they often ended up feeling dissatisfied and frustrated with the situation. Others, particularly spouse participants seemed bewildered that their situation had come to this and they had so little control over events:

"Some of them you can get on better with than others, because you've got to be ever so careful what you say. Because I gave Marjorie a Rennie the other day, and they're only spearmint and

peppermint and chalk, and she chomped it and there were little bits on her lip. And Sheila came in, and everything that happens they put in a book. And I had a little look at it. And it said: Jim and Claire came today to see Marjorie. Jim gave Marjorie Rennie without permission [laughs]. When we were in the dining room one day and Marjorie wasn't eating so well, her head were down like and I were trying to get her head up like that so I could put some in her mouth. And I says 'You're not very well today love.' I says 'Has somebody upset you?' And that went in the book. Jim pushing Marg's head back and he said that somebody's been upsetting her [laughs]. So I thought 'Well that's it.' Then the other day in the afternoon, I used to take her some Maltesers down and a tangerine, something like that see. And I said 'Come on love, have a Malteser'. and then I give her a tangerine. And then Sheila comes up and she says 'Jim', I said 'What?'. She says 'Have you been feeding Marjorie because she's not eating her dinner?' So I says 'Yes, I've been giving her Maltesers and a tangerine.' 'Oh' and that went in book. So I can't take her anything now. You feel as if you can't do anything.

Jim, Husband, Interview no. 25

Conflict in care - 'Battling it out' A small number of participants perceived no alternative to constantly registering complaints about care standards on behalf of their relative. Experience had taught them that this was their only hope of securing the desired outcome in relation to care practices. A surprising number of relatives described care staff as a barrier or hurdle which they had to overcome in order to ensure appropriate care for their relative and the use of metaphor in this respect was striking: participants talked of 'losing the battle', 'being up against it' of 'having to be on your mettle'. Indifference, inability or disinterest on the part of care staff meant that they perceived themselves as the only person operating with the best interests of their relative at heart. In this context, making a nuisance of themselves was the only strategy likely to have a positive effect.

“It is difficult to complain but it’s my mother I’m fighting for.”

Maria, Daughter, Interview no. 9

“We’ve got to make it the best. And if I’m going to be that relative from hell, well so be it.”

June, Daughter Interview no. 29

Summary of interview data and preliminary discussion

It is clear from these accounts that family caregivers experiences of helping their relative to move into a nursing home are extremely variable. However what is also clear is that the relatives interviewed as part of this study shared a very clear motivation throughout the various stages of the process: to ensure that the older person received the best care possible to enable them to maintain the highest possible quality of life.

A few issues are worth reiterating at this point as they have very clear implications for practice. These points will be further discussed in Chapter 6, along with other key issues emerging from both phases of the study.

The perception of many relatives that they were told that there was no alternative to nursing home placement is of concern, since this suggests a lack of involvement in, and ownership of, a life-changing decision. It could be that some relatives were attempting to legitimise the decision in order to assuage their own feelings of guilt and responsibility: however this was not my impression. I feel that the data provide clear evidence of a paternalistic approach on the part of some health-care professionals which fails to see family caregivers as partners in decision-making. This has important implications in relation to the likelihood of achieving a positive transition experience.

The inaccessibility of information about care homes and the lack of clear and explicit criteria to select a home leaves many relatives floundering, with the result that they fall back on informal networks for their knowledge. While these can be helpful, they are also limited in scope and several participants suggested that they would apply a more discriminating set of criteria if they were to select a home for a second time. This has obvious implications in terms of helping carers to prepare for the search and selection process. In terms of expertise, carers frequently return to a 'novice' stage when selecting a home and would benefit from clear advice and support. For many participants, this was most obviously lacking. While professionals cannot, of course, recommend particular homes, directing carers to potential sources of information, for example, inspection reports which are now public domain for both residential and nursing homes, would be potentially very useful.

The complexity of funding arrangements in Britain results in high levels of anxiety for older people and their families about whether they will be able to afford to move into, and remain at, the nursing home of their choice. This serves only to exacerbate an often tense situation and causes additional stress at what is most commonly a difficult time. Most relatives appeared to receive little guidance and support in relation to dealing with financial aspects of the move. Where such support was forthcoming, it made an important difference to the experience of this phase.

While most relatives found health and social care staff to be friendly, they acknowledged that they operate within a framework of limited resources and lack of education and training for their role. In some cases, this inhibited participants from seeking support for themselves directly from care staff. Some relatives were able to seek support from their families and friends but many found that this created further tensions and a few participants confided to me that this was the first opportunity they had experienced to talk about their feelings and emotions.

An important driver for most relatives at the time of the move to the nursing home was to ensure that staff were made familiar with older person's biography and

needs. However, most were unaware whether a comprehensive assessment of the older person's needs had been carried out. Furthermore, the majority had no recollection of being involved in the assessment process. These findings suggest that valuable opportunities to access expert knowledge about an older person's care, together with important biographical information are being missed.

Following the move into the home, most relatives find that it is left to them to establish a continuing role in care-giving, with very little guidance from staff. Most relatives receive little support to help them establish a pattern of visiting which meets both their needs and the needs of the resident. Furthermore, relatives generally have to take the initiative if they wish to continue to play an active role in caregiving. Most relatives have a clear understanding of the standard of care they would like their relative to receive but the reality of care frequently fails to meet these expectations. When this happens, they adopt a range of strategies in an attempt to close the gap between the care they would like and the care received. These range from asking questions in order to clarify the situation, showing staff how to deliver care, making requests and making formal complaints. However, a significant proportion of relatives appear to feel that they have no option but to keep quiet in order to avoid further jeopardising their relative's care.

At the beginning of this chapter, a series of continua were described which seemed to represent common experiences and perceptions of the process of helping an older person to move into a nursing home from the perspective of relatives. (Figure 4.1 p 100). There were indications that one of these - the extent to which relatives were able to work together with health and social care staff to ensure best care for the older person, was particularly important and often had consequences for the other experiences. Based upon the interview findings presented within this chapter, a summary of factors which appear to contribute to care experiences at the ends of each continuum at each phase of the move is presented in Figure 4.2. Factors which appear to motivate relatives during each phase of the process are summarised in Figure 4.3.

What is encouraging is that relatives' experiences during the initial phases of the move do not necessarily translate into similar experiences following the move into the care home. In other words, even where the initial decision to seek long-term care had been made in less than ideal circumstances and the search for a home was problematic, nonetheless positive experiences in a home with skilled and sensitive staff could result in relatives perceiving that the move was *'for the best'*. However, similarly, even when relatives began with a perception of the move to a nursing home as a positive choice, where care within the home did not meet their expectations, they were forced to reflect upon whether the decision had been the right one after all.

In Chapter 5 the findings of the case studies in three nursing homes are considered in light of the findings which emerged from the interview data.

Figure 4.2 Summary of factors contributing to relatives' experiences at each phase of the move to a nursing home


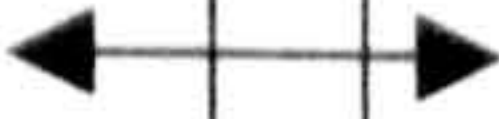
EXPERIENCES	PHASES OF THE TRANSITION		
	MAKING THE BEST OF IT	MAKING THE MOVE	MAKING IT BETTER
Under Pressure 	Difficult to involve the older person Conflicting views of family members Pressure to vacate a hospital bed Negative images of nursing homes Past promises and obligations	Changing homes perceived as impossible	Feeling of being monitored by care home staff Need to fit in with established routines within the home
	No pressure	Able to see nursing home care as a positive option Time to make the decision Older person able to be involved in discussions Anticipation of the move	Shared understanding that placement can be for a trial period
Working in the dark 	Lack of information about long-term care options Lack of information about nursing homes No criteria for choosing between homes	Information about routines and practices within the home is not readily available Relatives not involved in assessment and care planning	Care home staff do not spontaneously provide information about the resident's care Lack of information and preparation about what to expect sometimes resulting in unrealistic hopes for the future
	Being in the know	Clear, accurate information and advice from health care professionals Recommendations of specific homes from local people Prior personal experience of a home	Preparation in what to expect from the care home Involvement in assessment of older person's needs

Figure 4.2 (cont.) Summary of factors contributing to relatives' experiences at each phase of the move to a nursing home (cont.)

	MAKING THE BEST OF IT	MAKING THE MOVE	MAKING IT BETTER
Working apart ↕	Feeling that health and social care practitioners are motivated by different concerns Not being able to involve the older person in the decision Lack of agreement within family	Feeling that care staff are motivated by different concerns	Feeling that care staff are a 'barrier' that has to be overcome
Working together	Feeling that health and social care practitioners want the best for the older person Shared consistent views among family	Feeling that their expertise is recognised Feeling a partner in care	Sense of mutual respect and appreciation
Losing control ↕	Being told that nursing home admission is the only option Admission criteria/placement availability/fees limit choices	Care home staff take over all care without negotiation	Attempts to influence care practices are resisted by staff
Being in control	Gradual planned process following admissions for respite care Choice from a range of options Care home staff ask relatives how they want to be involved	Relative is able to contribute to care planning	Care staff respond to observations and concerns of relatives
Feeling unsupported ↕	No one available to talk through the decision with	Care home staff focus on needs of older person to the exclusion of relatives	Care home staff rarely take time to talk with relatives
Feeling supported	Availability of a health or social care practitioner who really understands at time of decision making	Care home staff provide relatives with an opportunity to talk through their needs and feelings at time of the move	Care home staff take an interest in relatives and provide regular opportunities to discuss needs and concerns

Figure 4.3 Principle motivators in relatives' experiences of nursing home entry

<p>Core category</p> <p>WANTING WHAT'S BEST FOR THEM</p>
<p>Making the best of things</p> <p>Making the right decision</p> <p>Making the right choice</p> <p style="padding-left: 40px;"><i>Gathering information</i></p> <p style="padding-left: 40px;"><i>Comparing options</i></p>
<p>Making the move</p> <p>Making it familiar</p> <p>Making them familiar</p> <p>Becoming familiar</p>
<p>Making it better</p> <p>Maintaining continuity</p> <p>Contributing to community</p> <p>Keeping an eye</p>

CHAPTER 5. LESSONS FROM THE CASE STUDIES: CREATING COMMUNITY WITHIN CARE HOMES

Introduction

Building on the previous chapter, attention is now turned to the data from the case studies. As described in the methods section, analyses of these data was intended to complement the interviews with relatives by exploring in greater detail the range of factors which either facilitated or inhibited the pursuit of 'best care' for the older person. The aim was to try and identify characteristic features of the homes which appeared to support, or otherwise, relatives' efforts to 'make it familiar' and to 'make it better'. Although, for the purposes of reporting, the interviews and the case studies appear in separate chapters, as will by now be apparent, these two sets of data inter-relate closely, with each enhancing the understanding of the total experience of the placement process. Therefore as the interview data were collected and analysed, the results informed the observations and interviews conducted at each of the case studies, and vice versa. This permitted a more nuanced explanation of the experiences of relatives, residents and staff in each of the homes and how these experiences were, in large part, inter-dependent. In analysing the case study data the relatives' desire to 'contribute to community' in their efforts to make a difference to the care received by the older person, provided one of the main sensitising concepts. Following detailed within and between case analyses the key process of 'creating community' emerged as a key concept as it became apparent that the interactions between the three main groups of participants (relatives, residents and staff), helped to 'create' the community within each home. The dominant type of community at each of the homes was also shaped by the way in which work was organised, how practice and the objectives of care were perceived, and the implicit values underpinning care. Following the analysis three main types of community were identified and exploring how these communities were created and sustained is the primary purpose of this chapter.

The chapter begins with a detailed within case analysis of each of the three nursing homes, before attention is turned to a cross-case comparison. This results in a synthesis detailing the three broad types of community. These should be seen primarily as heuristic devices which delineate the principle features and major orientations apparent in the homes. As with the data from the previous chapter, no one home was an 'ideal' representation of any of the communities, although as will become clear, each of the homes approximated most closely to one or other of the communities.

In order to provide a background and context, Table 5.1 identifies key features of the case study sites in terms of their number of places, ownership, location and buildings. These details are elaborated upon further in the text that follows.

Table 5.1 Key features of case study sites

CHARACTER-ISTIC	NURSING HOME A	NURSING HOME B	NURSING HOME C
Number/type of places	88 beds Dual registered 20 residential beds	60 beds Elderly frail	24 beds Recently registered as for elderly mentally ill (EMI) residents but many residents remain from time of previous registration
Ownership	Owner manages two homes	Part of a large national chain of 156 homes	One of nine homes in small local chain
Location	Poor suburb of large city	Affluent suburb on outskirts of city	Reasonably affluent area two miles from city centre
Buildings	Part conversion/part new build	Purpose built	Part conversion/part new build

A dominant impression from the observational work was that, while the three homes shared a similar day to day routine, and were also similar in terms of the range of residents' needs and dependency (although Nursing Home C had a few more residents who were mobile but cognitively frail), they differed from each other in a number of subtle ways. As data collection progressed, ideas began to emerge about the factors which were influencing the experience of living and working within the home as well as relatives' experiences, both of the admission process and of their subsequent role and relationships. Field notes and annotations were coded and analysed initially in relation to the following key features:

- ◆ design and layout of the home;
- ◆ pattern of the residents' day;
- ◆ patterns of work organisation;
- ◆ nature of relationships between residents and staff;
- ◆ nature of relationships between staff members;
- ◆ nature of relationships with visitors to the home (including relatives).

From these factors, the key values and objectives in operation within each home were inferred. Together, these indicators suggested the dominant culture within each home. However, it is important to point out here that it was not possible to check out these values explicitly with staff in each home (See Chapter 6).

Case Report 1: Nursing Home A

Introduction

The first case study focused upon a large, privately owned facility of 88 beds on the outskirts of a northern city. The owners managed one other home in a rural

area some sixty miles away. Part of the home was located within a converted eighteenth century hunting lodge, with the remaining rooms in a purpose-built attachment. In spite of the rather palatial impression afforded by the home's exterior, it was situated in one of the poorer areas of the city, although the social mix of residents was quite varied with a number of self-funding residents. The home had dual registration (i.e. it was registered for residential as well as nursing home beds) and approximately twenty places at any one time offered residential, rather than nursing home care.

Throughout the period of observation, the home was run as two separate units divided between the ground and upper floors of the facility, although staff moved regularly between the two units. The observation focused largely on the forty-four bed upper unit which provided exclusively nursing care. During the period of observation senior nursing staff, who were responsible for care on both floors, included a nurse manager, a deputy nurse manager responsible for in-service education and practice development and a liaison officer. This latter role involved liaising with local hospitals and social services departments in relation to the prospective admission of residents. All three senior nursing staff worked 'on the floor' as the only qualified nurse for either the upper or lower section of the home for at least three shifts per week. During the six-month period of observation, there were several changes among these senior personnel.

Design and layout

The layout of the home was potentially confusing to visitors, arranged over three floors with long inter-connecting corridors and several concealed stair-cases. A lift connecting floors had space for one wheel-chair. There was no sign-posting and no plan of the home to enable visitors and new members of staff to find their way around easily. There were four sitting rooms, two on each of the first and second floors. These were light and spacious but chairs were generally arranged around the walls which had the effect of limiting interaction between residents. In addition, the large entrance hall provided a further space where some residents like to sit during the day to 'watch the world go by'. The offices of the home owner

and nurse manager opened off this entrance hall, as did a small office serving as the nursing station for the lower floor.

Dining rooms (two on the ground floor and one on the first floor) were used only for meals, and tables were laid for the next meal as soon as a meal had been completed. A central kitchen was situated just behind the entrance hall and there was a large central laundry further along the downstairs main corridor. A central court-yard provided a pleasant and sheltered place to sit during fine days and a garden area to the front of the home was accessible to residents and visitors.

Rooms in the extension were all single rooms but were quite small with barely sufficient space for a single bed, a chair and a television. In many of these rooms, space was so limited that the bed needed to be pushed up against the wardrobe during the day, limiting access. None of these rooms were en-suite and toilet and bathroom facilities were shared by men and women. Residents' rooms in the older part of the home were more variable in size and some were very large. Most had had en-suite facilities installed. Two double rooms in the old part of the house were occupied by married couples. The larger en-suite rooms were more expensive and were occupied mainly by residents who were self-funding.

Throughout, the home was well decorated in bright colours with contrasting floral soft furnishings. The impression on first arriving at the home was one of comfort and tranquillity. A handyman/gardener was employed to work full-time in the home and there was a rolling programme of decoration and repair.

Pattern of the day

The morning shift commenced at 07.15 with the carers and registered nurse arriving and signing in. Carers then immediately began helping those residents not yet awake to wash and dress while the registered general nurse (RGN) received a handover report from the night RGN. Once this report was completed, the RGN began preparing medications for the morning drug round. These were dispensed into medicine pots in the treatment room together with a small slip of paper with the resident's name. The pots were then distributed to residents in the dining room

while they were having breakfast, often by carers. Carers escorted residents to the dining room once they were dressed to wait for breakfast which was normally served at 08.00am. Although the dining room on the first floor was a large area, there was insufficient space to seat forty-four residents comfortably and moving everyone in involved a great deal of manoeuvring with wheelchairs. Residents tended to sit in the same spot for all their meals and there was some resentment if this pattern was not adhered to by the carers. Breakfast included a choice of cereal, bread and butter and a cooked option such as a poached egg. Toast was not available and this was frequently lamented by some of the residents. Food was delivered to the dining room in a hot trolley from a central kitchen downstairs and served by ancillary workers assisted by carers. The pattern of meals was similar for lunch and tea. There was no obvious choice of meal at lunch and tea-time, except for the most articulate residents, with carers deciding on the appropriate option for the majority of residents.

Meal-times were usually chaotic and rushed. A radio in the corner of the room was invariably tuned to pop music which added to the sense of noise and bustle. Those residents who needed help to eat sat together on one table and were normally served first. Large plastic aprons were used to protect the clothes of these residents from spillages. There was very little interaction between residents during meal-times, while staff tended to chat amongst themselves. Some residents had expressed a preference to eat in their rooms and this was generally adhered to, although staff did attempt to persuade residents to go to the dining room whenever possible.

After breakfast, residents were taken to one of two lounges on the upper floor or returned to their rooms, stopping at the toilet on the way if necessary. Residents tended to occupy the same spot in each lounge and again, resentment was expressed if a resident was inadvertently placed in the wrong spot. The majority of residents needed help to move about the home and those who were able to express a preference were normally able to sit either in a lounge or in their room according to their choice. Carers then made beds and tidied rooms until 9.00am when all staff congregated in the office for a hot drink and to listen to a report on

residents delivered by the registered nurse in charge. Details were limited, with the report on up to forty-four residents usually taking 10 – 15 minutes. The report normally took the format of the RGN mentioning each resident by name and then saying '*fine*' or '*She's OK*', unless there was anything specific to report in relation to a change in the resident's condition or a planned visit, such as an outpatient appointment. Care plans were rarely referred to during verbal reports and there was little discussion of specific care needs.

Although carers were designated to work in a particular area of the home each shift, they were allocated in pairs and no carer had responsibility for assessing the needs of an individual resident, meeting these needs and reporting back to the nurse in charge. Residents were offered a bath on a weekly basis and this duty was allocated to care assistants at the morning report. Apart from this task which relates to individual residents, care assistants generally seemed to 'muck in', responding to residents' expressed needs on an ad hoc basis.

Following the morning report, carers completed the round of bed-making and tidying rooms and began to take their individual breaks in turn. The RGN was usually occupied in the office with paperwork and telephone calls. Contact with residents was usually restricted to wound dressings and checking a resident's condition if a carer noticed a change. Residents were largely left sitting in the lounges with the television invariably switched on. Coffee (no choice of tea and no biscuits) was served by carers anywhere between 10.30 and 11.30. From about 11.15, carers started taking residents to the toilet and moving them back into the dining room for lunch, the main meal of the day at 12.00. Lunch was usually over and the dining-room cleared by 12.30.

The home employed a full-time activities co-ordinator but activities were largely directed to the residential unit downstairs and she rarely appeared upstairs where the more frail residents lived. Occasionally, the more mobile residents were taken on an outing to the local shopping centre, and, once during the period of observation, for a pub lunch in the country. However, for the majority of residents the time between meals was spent sitting or sleeping in one of the lounge areas.

Afternoon staff arrived at 2.15 and again there was a short handover report. A cup of tea was served by the afternoon staff immediately after report and carers were involved in sorting residents' laundry and bathing residents according to the daily schedule. All residents were bathed once a week. Occasionally, carers would sit with residents and engage them in conversation, but more frequently, they would use time between direct caregiving tasks and routine events to have a cup of tea in the office. Conversation during these 'unofficial' breaks was largely social and residents' needs were rarely discussed. At about 4.00pm residents were once again moved into the dining room and tea, usually soup and sandwiches followed by cake, was served. Some residents were put into bed for the night immediately following this meal. Others returned to one of the lounges or to their own rooms. Staff took breaks between six and seven and residents were helped to bed until the night staff arrived at 21.30. Carers were then usually allowed to go home while the RGN gave report.

Experiences of care and relationships for residents

Although most residents said that they would prefer to be in their own homes, nearly everyone that I spoke with felt they had adjusted to living at the home and felt that the staff were, on the whole, kind and helpful. Residents commented on the comfort and decor within the home and most liked their rooms. When asked if there was anything about the home which they would like to change, most residents found it hard to think of something. However, some residents felt that the routine within the home meant that on occasions their individual needs were neglected. The lack of choice over whether to have a wash or a bath was one example with residents themselves perceiving that they really had no option about this:

“You’ve got to have a bath whether you like it or not. They tell you in the morning whether you are having a bath or not.”

For one resident, this lack of choice was most acutely felt in relation to being sat with particular residents in the dining room:

“Well there’s a table next to us and there’s two women - ooh and they’re terrible. They sit staring at us. Well they’ve put one of them on our table this morning and we weren’t very pleased with that. Our names are meant to be on our table. There’s five of us on our table and we’re all comfortable. But she spoilt it this morning.”

Such lack of personal control over day to day activities was often acutely felt.

One conversation I had with several female residents in the lounge turned to cooking and how they missed preparing family meals. Because of the central location of the kitchen, and also because of health and safety regulations, residents were not allowed to take part in the preparation of food. Furthermore, one of the main things they missed about living in the home was not being able to have a cup of tea when they wanted one:

“I’ve been in (N) hospital a while since, but if you happened to say ‘Oh I can’t go to sleep’, they go round in the night and she’d say ‘Wait a minute’. And she’d bring you a lovely mug of tea. But they won’t do that here. I only asked once and she said ‘I’ve my work to do, get to sleep’. Oh she was nasty. ‘I’ve my work to do. I can’t be getting you cups of tea’”.

Some female residents said that they would prefer female carers to perform personal care tasks whenever possible and felt this had never been discussed with them. The home employed both male and female carers and all carers worked with all the residents.

Most residents who could indicate their views wished for more activities to prevent boredom. Outings, when they happened, were greatly appreciated and most residents who could express a preference wished that these could happen more often. Time to ‘chat’ with staff was highly valued but happened less frequently than residents would like.

"I don't get no company that's the point, I'm on my own. I might as well be at home in my own bedroom. People don't take the time to talk. That's the trouble, I've nobody to talk to. I'm on my own so much and I like a bit of company. I've nobody at home. Nobody comes now to see me. Still I suppose they have other things to do."

Even when staff did not have the resources for formal activities and outings, just 'popping in' to check that residents were all right was appreciated:

"I'd like someone to occasionally come in to see if there's anything I want doing. Even if its only a few minutes, say ten minutes or so just to sort things out a little bit. It doesn't need to be at a fixed time - anytime would be all right. I'm always at home".

Mealtimes were very important to residents, providing a landmark in the day. However, many were critical of the food:

"Sometimes the food is awful. We get a lot of parsnips - nobody eats them but they will insist on sending them."

"I haven't been very happy with the food and it doesn't seem to be getting any better. If there were a bit of bacon and tomato or boiled egg now and again, but not hard boiled. Its a long time since you had something like that."

While on the whole, residents perceived staff as cheerful, kind and friendly, some residents appeared to take to heart perceived criticism from members of staff:

"I don't use the commode very often at night - on average about twice. To me, I'm a little bit on the nervous side and there's one - she's always rushing me. The other night I said 'Oh for goodness sake go out a bit' because if they go out I can manage. Now some of them are very very good - they say 'Oh we'll just have a little

walk' and its all the difference. But this one - she burst out the other night, went straight to the sister and complained about me and the sister came in here and she thoroughly tore me off a strip which I thought wasn't very nice. I mean I pay my money to be looked after, not to be dictated to."

For the majority of residents, all their interests were focused within the home, and what may have seemed quite trivial incidents to staff could assume enormous significance for residents. However, most residents spoke warmly of individual members of staff and obviously appreciated the special relationships they had with them.

"Ann (staff nurse) came to say goodnight to me because she wasn't going to see me for two days."

"I'm very fond of Mary (care assistant). She's slow but she's very thorough. Whatever you ask its done. I like Mary. When she's here everything seems to run so smoothly."

Experiences of care and relationships for relatives

In spite of an open visiting policy, a notable feature of this nursing home was the absence of regular visitors for most residents. Certainly, fewer visitors were observed here than at the two other case study sites. This may be a consequence of the layout of the home and the fact that the lounges were crowded with residents during the day so that visitors tended to take relatives to their rooms. However, there was clearly a sense that relatives were 'visitors' rather than part of the community of the home. This is illustrated by the following extract from field-notes.

One of the residents, UH had visitors in her room at about 6.00pm. She was already in bed for the night and was positioned on her side facing towards the wall. They were standing as there were no chairs in the room. I knocked on the door and asked if they would

like me to bring them some chairs. They seemed very pleased and grateful. I overheard the woman say 'no-one's ever done that before'. I recalled that earlier in the report, J (RGN) had talked about this lady's prolapse and how she had been referred by her GP for an urgent gynaecological opinion the previous day. The daughter had rung the home to check on the outcome and was told that surgery was unlikely as she was felt to be an anaesthetic risk. The daughter had then rung the GP who had contacted the home to discuss her call. The staff were upset that she had felt it necessary to ring the GP herself and J referred to them as 'the relatives from hell'.

Because of the layout of the home, it was quite possible for relatives to visit and leave again without ever seeing or being seen by a member of staff. The nurses' office was situated at one end of a long corridor some distance from the resident lounges and most of the residents' rooms. Most visitors would have had to actively seek out a member of staff if they wanted to discuss anything.

A social event to which residents' families were invited provides an illustration of interactions with outside visitors. A Bonfire Party was advertised a month in advance and relatives were invited to purchase tickets for a 'pie and peas' supper followed by fireworks in the grounds. The party was advertised to start at 6.30pm; however residents were served their final meal of the day at 4.00pm as usual and did not eat with the few relatives who attended. Some of the residents were helped outside to watch the fireworks and some watched from the lounges. However, some residents told me that they had not been offered the opportunity to attend. The majority of the visitors were friends and relatives of staff members. Most visitors left as soon as the firework display was complete at about 7.30pm. Although the party was a happy and enjoyable event for those who attended, I felt that more could have been made of the occasion.

The degree to which I was able to engage visitors in conversation at this home was limited by two factors:

- ◆ the small number of visitors;
- ◆ the fact that residents often received visitors in their rooms and it would have felt intrusive to enter during this time.

Furthermore, most visitors spent a relatively brief amount of time at the home which further limited the time for conversation. Overall the impression was that visitors were transitory and that they did not feel part of the community of the home.

Experiences and relationships for staff

Informal discussions with individual members of staff suggested that they were mostly committed to the residents at Nursing Home A and enjoyed their work with older people. Carers in particular mentioned the sense of achievement which they felt at the end of a shift and how they were able to take pride in their work. However, staff turnover among all grades of staff was high and those staff that stayed were mainly mature women with families, who lived locally. Qualified staff appeared less satisfied with their working conditions, partly because they frequently had to cover for staff vacancies and absences. Again turnover was high with heavy dependency on agency staff.

Most staff felt that personal care for residents, in relation to meeting hygiene needs and looking after personal clothing for example, was of a high standard. However, a number of common concerns were raised. A general worry was that there were insufficient carers on each shift to be able to provide the sort of care they would like. This was often due to staff sickness or absence leaving a shortfall rather than systematic under-staffing. It also emerged that there were some changes which might save staff time and hence free up time for other activities. One example was the call bell system which rang on all three floors whenever a resident pressed their call button. This meant that staff had to go back to the nurses station from wherever they were in the home to check where the call had originated from.

Carers suggested that having more staff on each shift would mean that they could spend more time with residents. Having time to sit and talk with residents and finding out more about them was felt to be of vital importance to maintaining their quality of life.

“It’s important to make them laugh, have good times with them. It’s nice to sit down with them when you can but when you haven’t got time. You think what must they be feeling like, just sat there watching telly all day with no one to talk to, just four walls?”

Some felt that structured activities were directed towards a minority of more able residents and that the majority of residents had very little to occupy them:

“There should be more activities available, something they can do. Perhaps some of them would like to knit. There should be something they can do like ask for it or just get up and get it. Because they’re that bored some of them it must finish them off. They’re just looking at the walls”

“We need to think what would I like? The activities programme seems to focus on the residents downstairs (residential care)”.

In conversation with me, carers expressed ideas for enhancing the quality of life of residents. For example, suggestions were made for a pet visiting scheme and a fish tank in each sitting area. Opportunities to listen to music rather than watching television all day were also mentioned. However, these carers seemed to have no idea how to make these things happen and perceived all sorts of barriers to any kind of change, such as the need for additional resources and the fact that *‘people can’t be bothered’*.

Many staff members mentioned the importance of being able to develop special relationships with individual residents but felt that staff shortages, and therefore lack of time, militated against this. Another issue raised by many care assistants

was that they would like more information about individual residents, particularly about their nursing needs, and about the conditions affecting them. Some staff felt that very little information was provided during the handover report and described how qualified staff tended to use medical terms and 'jargon' which they didn't understand. Several carers suggested that the handover report at 07.15 should be to all staff as they sometimes find themselves providing care to residents without up to date information.

"You have to find out about the residents as you go. I think it would be good if the qualified staff would sit you down and run through the care plans with you on a daily basis, to get to know what their needs are. But that's not being done."

Many care assistants also felt the need for more detailed biographical information about residents.

"We need more information about what jobs they used to do when they were younger. It would be nice to have a little booklet or something to just show us what life they had. They were like us once."

Several care assistants felt that they could be involved in gathering this information and sharing it during report: however, others felt that they might lack the confidence to do this.

The lack of basic equipment and the poor condition of many items of equipment, particularly wheelchairs was another area of concern for staff. Many wheelchairs were missing foot-plates and had non-functioning brakes. Routine practices for moving and handling residents were criticised, with some staff feeling that they were putting themselves at risk by continuing to manually lift heavy residents. Furthermore, some staff members felt that residents were left sitting in wheelchairs for too long, particularly at meal-times and that residents should be helped to transfer to dining chairs in the dining room. Several members of staff mentioned

the need for more supplies around the home, particularly toiletries, and suggested that these should be readily available in bathrooms. This would save time in running around to fetch essential items when helping residents to meet hygiene needs.

A number of care assistants and qualified staff commented on the way in which the routine within the home seemed to dominate the residents' day, particularly in relation to meal-times. Several members of staff mentioned the pressure which they felt to '*get the work done*', particularly within the morning shift, when some of this work could easily be transferred to the afternoon. Meal-times were felt to be 'chaotic' and 'rushed', although this did vary from day to day.

"Meal-times are chaotic but it helps when there are less residents. It comes down to who is doing this, who is doing that. You don't know who is doing what. How do you know who has had their dinner?"

Some carers mentioned concerns about the way in which other members of staff talked to residents and failed to treat them with respect. This related also to protecting residents' rights to dignity and privacy, for example always remembering to knock and wait for a reply (where appropriate) before entering a resident's room. Talking to residents while providing personal care was felt to be particularly important.

While relationships between members of staff were generally described as '*fine*', there was some criticism for the hierarchy of roles within the home. In particular, the system of having differently coloured belts for care assistants of different seniority was disliked. Some care assistants felt that this failed to reflect the experience they had gained working in other homes:

"Its not as if I've just come into the job and I don't know what I'm doing and I need to be supervised. I feel like sometimes I'm being watched more than others."

“If you have two qualified staff on upstairs (for forty-four residents) that’s OK. It depends which qualified are on. If they’re hands on its OK although the qualified staff could help us more. Since I’ve been here I’ve had a run-in with one of the qualifieds because they talked down to me and I didn’t like it. If they want respect they’ve got to respect us as well. We know these residents better than they do. We’re with them seven hours a day and if they’re ill we can tell. We’re not qualified but you know when they’re not right don’t you.”

However, care assistants also recognised the pressures on qualified staff, particularly when there was only one nurse covering a floor. Most carers said they would welcome more clinical supervision from qualified staff and the opportunity to work alongside qualified staff more, particularly those undertaking National Vocational Qualifications (NVQs). Suggestions were made for further training including: first aid; coping with death and dying; pressure area care; continence care and specific conditions such as Parkinson’s disease and stroke. However, with no designated budget for staff education, staff were dependent on sessions provided free-of-charge by local Trusts or on in-house provision, which seemed virtually non-existent during the period of observation. Care assistants were encouraged to register for National Vocational Qualifications but were required to pay the £45.00 registration fee themselves. On an hourly pay rate of £2.60, this was beyond the resources of the majority.

Summary: impressions from Case Study 1

The size and layout of this home appeared to be important factors influencing the way relationships developed. Although the home was effectively divided into two, a unit of forty-four residents still presented major challenges to continuity of care and valuing personhood. Recent changes in senior management and rapid staff turnover had militated against a sense of ‘team’ and it was difficult for carers to have a voice, or to feel that they could change anything. Frequent changes in managerial roles during the period of observation limited enthusiasm for practice development and there was a sense of ‘fire-fighting’ - that the main objective was

to get through each shift without any disasters. This was confirmed in discussion with qualified staff.

Access to resources which might change this situation was limited: the nurse manager had no budget for staff education and training and at the time of the observations, carers were being paid less than the subsequently introduced national minimum wage. Qualified staff had to battle for new equipment, although the décor of the home was well maintained. In view of these constraints it is a credit to the staff that they were able to remain committed to the care of the older people living here. Nonetheless, their interactions with residents and their relatives frequently suggested a lack of awareness of the needs of older people requiring continuing care, particularly if they were to maintain a reasonable quality of life. Residents' choices about their day to day routine were limited, particularly for those residents who were unable to express their wishes easily. There was a general lack of stimulation for all but a few residents and most spent their days sitting or slumped in chairs in the day room with little to interrupt the routine pattern of the day. A tendency to view resident's families as 'outsiders' and a potential threat, rather than as active partners in care limited the extent to which the needs of relatives were recognised and engaged with. The overall impression was of an isolated community with only tenuous links with the outside world.

Case Study Report 2: Nursing Home B

Introduction

The second case study focused upon a purpose-built nursing home for up to sixty residents situated in an affluent suburb of the city. This home is part of a large national chain which owns and operates 156 care homes throughout the UK. The corporate influence was apparent in many of the features of the home and managerial staff reported that some decisions lay outside their remit. Regional managers visited the home approximately monthly and a regional programme of staff training was in operation. Managerial functions were divided between a full-time clinical nurse manager and a full-time business manager. Relationships at this level were mutually supportive and the collaboration appeared to work

extremely well. A deputy nurse manager worked closely with the clinical nurse manager on practice development issues and staff recruitment.

The clientele here were mostly self-funding and many were from affluent backgrounds. However, there was a wide range of dependency, with some residents totally dependent on nursing care. The home was not able to accommodate older people with dementia who were still mobile, partly because of an 'open-door' policy which would have raised issues of safety for 'wandering' residents and partly because, as the nurse manager suggested, *'the other residents wouldn't accept them'*. The nurse manager pointed out that, because of their privileged backgrounds, many of the residents were used to having paid help at home and consequently had very high expectations of their care.

Design and layout

This home was a purpose-built facility completed approximately three years ago. Laid out over two identical floors, the home was easy to navigate with communal areas and offices located centrally and residents rooms either side of two corridors extending from two sides. Rooms were large and spacious and all were en-suite. Décor was similar for each room but most residents had personalised their private space with ornaments, soft furnishings and some larger items of furniture. Twenty of the sixty rooms had been designed initially as double rooms, but these were gradually being converted to 'Premiere' rooms available with a supplement cost since double rooms had proved virtually impossible to allocate. Occasionally, married couples were accommodated in these rooms, mostly for short-term respite care. The reception area located in the lobby opened into the administrator's office so there was usually someone to welcome visitors. A comfortable sofa situated in the lobby also provided a popular spot for residents to sit and watch the world go by.

A large lounge on each floor was furnished with comfortable arm-chairs, one or two sofas, a large TV, music centre and video. Corners of each lounge had cupboards with large-print books, games and jigsaws available. A smaller sitting-room was designated as a smoking area and this was well used by residents and

visitors alike. The dining room was also large and spacious and had a servery at one end. All food was prepared in the kitchen area in the basement and delivered to the servery in dumb waiters before being transferred to heated trolleys. Carers served the food to residents at their tables.

Staff accommodation was situated in the basement and included two rest rooms and separate changing rooms and toilets for men and women. The domestic supervisor and catering manager had offices here and a large laundry and hairdressing salon completed the 'service' areas. The home had pleasant grounds with outside seating and a sunny patio area adjacent to the dining room was furnished with a barbecue, chairs and tables.

A sophisticated staff call system involved all staff carrying pagers for the period of their shift. When a resident pressed the call bell for attention the pager 'beeped' discretely and displayed information about the source of the message. Simultaneously, an electronic record was created of when the call button was pressed and when it was responded to and cancelled. This allowed staff to audit response times.

Pattern of the day

The early shift arrived at 07.45 and a brief handover report was given by the night RGN with day staff standing at the nurses' station. This report focused largely on how well each resident had slept and limited information was provided about general objectives of care. The nurse manager reported that monthly meetings with trained staff provided the main forum for detailed discussion of residents needs and plans of care. Information was then cascaded from this meeting to senior carers and carers as appropriate.

Following the brief morning report, carers were allocated to work along each corridor with one carer identified to prepare and distribute breakfasts. Carers coordinated this division of labour using work allocation sheets prepared by the nurse manager on a weekly basis: however, they did not always appear to work with residents for whom they were the key-worker. Carers appeared to be very

familiar with the routine and required little direction from the RGN on duty. While the carers began to help residents to get out of bed, washed and dressed, the RGN began to make phone calls and arrange treatments. Morning medications were usually administered by the night staff but on occasion were administered by the RGN on the morning shift. An individualised blister pack system was in operation with all medicines in tablet form pre-packed at the pharmacy. This system seemed to work well and made drug administration smooth and efficient. A small number of residents were self-medicating. Some residents had already been helped to wash and dress by the night staff and there appeared to be a genuine attempt to allow residents to get up at their own preferred time. Breakfast was prepared on trays by one carer using a card system whereby each resident had recorded their preferred breakfast. Trays were delivered to each resident's room once they were ready: however, accurate co-ordination was not always possible and occasionally tea and toast were cold by the time residents were ready. A small number of residents chose to eat breakfast in the dining room, usually alone.

Following breakfast, most residents chose to remain in their rooms although some moved regularly to one of the lounges. The home employed a full-time activities co-ordinator and a detailed programme of events was produced on a monthly basis. A copy of the programme was delivered to each resident's room and was also pinned to a notice board on each floor. Activities included exercise classes, reminiscence and watching videos together. Occasional concerts were also arranged. The local branch of the University of the Third Age held weekly meetings in the upstairs lounge and some of the more cognitively able residents attended regularly. The home had a 'people carrier' vehicle and outings were arranged on a weekly basis, usually trips out into the Derbyshire countryside.

Staff took 15 minute breaks between 09.00 and 10.00. Carers then served coffee/tea and biscuits between 10.30 and 11.00. Shortly after twelve o'clock, carers started to help residents to go to the toilet and then to move into the dining room where lunch was served at 12.30. This was a three-course meal with two choices for each course. Residents generally chose to sit in the same place for each meal and there was usually a pleasant buzz of social conversation. However,

food service was time-consuming and the use of printed lists of menus to guide plating of food meant that some residents had usually finished a course before others on their table had been served. The nurse manager reported that there had been numerous attempts to rectify this situation, for example by trying to serve all the residents at one table at a time. However, residents did not always arrive for their meal at the same time or chose to sit at a different table so this had proved difficult. The nurse manager identified food and meal-times as the aspects of care which prompted most complaints and attributed this to the difficulties of trying to ensure that menus and meal-time arrangements suited all tastes and preferences.

During lunch, the RGN on duty was again involved in administering medications in the dining room but carers appeared to take primary responsibility for supervision of the food-serving process.

Following lunch most residents returned to their rooms or to one of the lounges. Staff working the afternoon shift arrived at 13.45 and all staff were involved in a brief handover report before morning staff left. Usually, two or three staff members were working long shifts (07.45 – 20.00) and these staff had a lunch break. Some residents were bathed during the afternoon and any outstanding wound dressings were completed by the RGN. Afternoon tea was served at 15.15 and tea in the dining room at 5.00pm. Staff then usually took a break together in the dining room before starting to help those residents who wished to go to bed. Again, there appeared to be a commitment to enabling those residents who could express a preference to go to bed when they wished. Night staff arrived at 19.45 and day staff completed their shift at 20.00 following a brief handover report.

Experiences of care and relationships for residents

Residents' views of living at Nursing Home B appeared to be mixed with many residents expressing great satisfaction with every aspect of the care and attention they received. These residents obviously felt that staff had made every effort to get to know their individual needs:

“They treat me like I’m me, not just another one”

Most residents spoke warmly of individual staff members. However, others were more circumspect and in particular regretted the fact that staff had so little time to spend talking with them, as noted in the following field-note describing a conversation with a resident:

She seemed generally quite happy with the care in the home but said that no-one ever comes into her room to talk to her as I was. She said it was important to build up trust with the staff. One thing which she said would improve communication was if there was a room where the trained staff sat and you could just go in and know that you could talk with them. She found the nurses' station a real barrier - nurses seem to sit behind it doing paper-work all day.

Although residents' needs for physical care were carefully attended to, some residents felt that staff were less aware of their need for social and emotional support. This was supported by an examination of the nursing documentation which revealed few entries in relation to social and psychological care needs. The nurse manager explained that information on each resident's social history was maintained separately by the activities co-ordinator and that social needs were discussed at the monthly review meetings. While individual members of staff appeared to have close relationships with residents and knew a great deal about them, there was little obvious sharing of this information and discussion about the best way to meet their needs on a day-to-day basis. The nurse manager explained that these discussions took place between qualified staff at the monthly meetings and that such information was shared with the carers on a 'need to know' basis. Some relatives had expressed concern about carers having access to detailed clinical information about residents' needs and this had caused senior staff to reconsider the level of information shared with carers.

Although some close relationships had developed between residents, on the whole these were somewhat reserved. Some residents were quite assertive about their needs and wishes and this frequently had consequences for other residents. In particular, residents were observed being quite unpleasant to each other when they

felt their own wishes were not being respected - for example when staff sat a new resident at a table with an established resident without her consent, the established resident was extremely rude to the new resident, to that lady's obvious distress. However, there were also examples of supportive relationships between residents and, in particular, strong support for residents from some visitors.

Experiences of care and relationships for relatives

Visitors were much more in evidence here than at Nursing Home A. This was partly because the layout of the home meant that most visitors passed by the nurses station on their way into the home. However, observations and conversation with visitors suggested that it also resulted from the fact that many of the regular visitors were middle-aged women who were at home during the day and therefore had more time available. Again there was an open visiting policy and visitors were made to feel very welcome. There appeared to be little obvious negotiation about the role which relatives would like to continue to play in the life of a resident, although the senior nurse manager reported that this assessment usually took place during the pre-admission visit and during the first few days of admission. Information about the named nurse and key-worker were displayed in each resident's room together with the date of the next care plan review. The nurse manager reported that relatives were encouraged to mention any concerns or information to the named nurse in advance of the review, although they are not invited to meet formally with the staff to discuss a resident's plan of care.

A small number of relatives who visited the home very regularly seemed to make themselves feel at home, for example helping themselves to tea and coffee in the dining room and smoking with other residents and relatives in the smoking lounge. One daughter was observed occasionally having coffee with staff in the staff rest room. These relatives also made an obvious effort to get to know other relatives and to make relationships with other residents. Many visitors however were received in residents' individual rooms and did not appear to participate in the wider life of the home, although this was probably through their own choice as staff were very receptive to visitors.

Informal conversations with visitors suggested that most were very happy with the standards of care in the home and found the environment extremely pleasant. A small minority felt that the home's position within a large corporate organisation was somewhat at odds with the 'homely' philosophy which they had sought for their relative; however, this was a minority view. Relationships between relatives and staff were generally friendly and trusting, although one relative highlighted the difficulty of discussing any concerns with the staff for fear of upsetting them. One relative suggested that the home provided an appropriate environment for more able residents but those who could not get about were often isolated:

"That makes all the difference – if you can get about you're all right."

The way in which visitors could enhance quality of life for all residents, not just their own relative, was illustrated by the following fieldnote describing a Christmas concert:

Christmas concert. Well attended by residents but very few relatives/visitors (3). Also few staff members joined the group – only D (activities co-ordinator) and one carer from upstairs. Some visitors who did arrive tried to have a conversation in the lounge while the concert was going on, much to the chagrin of some of the others. The entertainer was very versatile, played a range of instruments and sang along to a Karaoke machine. Good range of material which seemed to be appreciated by most, but not all of the residents. Heard two residents afterwards saying they thought it would have been more Christmas carols. However, there was a very pleasant atmosphere during the concert and the audience warmed up as things went along. They had tea mid-way through which made it a pleasant social occasion and by the end there was a lot of foot-tapping, table-tapping and even some of the more reserved residents had become quite animated. Some residents obviously found some tunes very evocative and emotional and there were tears. I noticed during the concert how some relatives who

visit very regularly provide stimulation and conversation for other residents. People coming in from outside on a regular basis so that residents have a chance to build up a relationship with them is like a link with the outside world. This works two ways: having more able residents with social skills who can engage more readily seems to make visiting easier for relatives of cognitively impaired residents. So there is mutual benefit.

Its a shame that more of the staff didn't participate: the nurse manager reported that this was unusual but that staff sometimes took the opportunity to catch up with other work once residents were engaged in an activity. However, if staff join in it seems to create more of a sense of community.

A further field-note suggested that staff could also invest a great deal of effort into creating a sense of community:

Attended Christmas Fayre. This was a really pleasant event which seemed to work extremely well. It was obvious that staff had put a great deal of effort in, often in their own time. Many staff were there off duty. Some people were manning craft stalls. There were lots of visitors and it really seemed like 'home from home'. Tea, coffee, cakes and soft drinks were available to purchase in the dining room and many families participated. Some children played carols intermittently on brass instruments but one or two residents seemed a bit overwhelmed by this. One complained about the noise and one was in tears, possibly because the tunes evoked difficult emotions. It struck me how difficult it is to get it right for everyone. I was also surprised by the number of visitors. Space was a problem with lots of people and wheelchairs. However, the whole event had a nice community feel.

Staff experiences and relationships

Staff were generally allocated to work either upstairs or downstairs within the home for a period of several months and this provided some continuity for residents and their families. However, occasionally qualified nurses had to provide cover for the opposite unit and this could result in difficulties. For example the deputy matron described the consequences of having to cover a qualified nurse's sick leave:

"I've got five residents upstairs who I'm supposed to be primary nurse for and I know very little about them."

Relationships between staff appeared to be generally good with carers very willing to help each other out and on the whole there was an air of supportive informality. There was a core team of stable staff, many of whom had worked at the home since it opened. In particular there was little turnover amongst qualified staff. These staff generally enjoyed their work and liked the atmosphere of the home. However, in contrast recruitment and retention of carers was a constant challenge, largely because of the home's location within an affluent suburb which meant that the majority of carers had to travel long distances. Recruiting carers of a sufficiently high calibre was a continual problem and occupied a large part of the clinical nurse manager's time. Because the home was part of a large chain, it was also possible that senior staff would be called away to cover at other homes within the locality and this also affected continuity.

Staff here appeared to feel much more empowered to introduce changes which might enhance the quality of life for residents. For example, the day before my first visit had witnessed the opening of a 'gnome village' to one side of the patio outside the dining room. The clinical nurse manager described how this had developed from a brainstorming session when *'everyone had been feeling a bit fed up'*. Staff and relatives had been informed of the plan and had been invited to contribute a plaster gnome. The home 'handyman' then created the village (cottages, bridges, fishpond etc.) in his own time. A barbecue party was held to celebrate the opening of the village. It was obvious that this event had provided a

great deal of enjoyment for all involved. The 'village' also created a talking point and a sense of 'community' and 'belonging'.

Overall, staff seemed satisfied with the standards of care they were able to provide while acknowledging that they would like more time to sit and talk with residents. Although named nurse and key-worker systems were in operation, most carers did not seem to identify particularly with individual residents and in fact felt that this would not be particularly helpful:

"We all need to be able to look after everyone so we need to get to know them all. Its no use only knowing a few."

Staff education and training were given a high profile and members of staff were supported to extend their professional qualifications through external agencies. In-service training sessions were held regularly but tended to focus upon health and safety and 'customer care' issues rather than issues relating more specifically to quality of life.

The home had recently begun to offer five-week placements for student nurses undertaking an advanced diploma in nursing studies. These placements had evaluated well and seemed to offer opportunities for closer links with the local school of nursing and midwifery. However, students were observed being sent to a different part of the home, away from their designated mentor, when the home was short of staff.

Summary: impressions from Case Study 2

Nursing Home B provided a very comfortable environment in a pleasant suburban setting. First impressions were of a luxury class hotel and décor and fittings were of a high standard. However, the atmosphere was informal and friendly with visitors to the home made very welcome. Many of the residents were from affluent backgrounds and were self-funding and as a consequence were quite assertive and on occasions demanding. It is possible that this may have limited the extent to which staff could develop collaborative plans of care. Standards of

physical care were extremely high. However, a significant proportion of residents felt that their needs for social contact and conversation were not being fully met. This must be seen in the context of the nurse manager's assertion that many residents preferred the privacy of their own rooms and resisted staff attempts to encourage them to socialise more. Some residents struggled to reconcile differences with other residents and obviously found it challenging to live in such close proximity with people they did not particularly get on with. Privacy was afforded a high priority as suggested by the nurse manager's succinct description of the home's philosophy of care:

"Its not an institution. We have no set regimes. It's their home. We're coming to their home to care for them. We want to help them to maintain their privacy and their dignity."

Case Study Report 3: Nursing Home C

Introduction

This was the smallest of the three homes in the study with 24 places. Opened two years previously, the home had recently re-registered to provide care predominantly for elderly residents with a mental illness (EMI), but many residents remained from the time of previous registration having made an active decision to stay. When the period of observation began the nurse manager had been in post for three months. The home was full with a waiting list of eight.

Nursing Home C was one of small chain of nine homes within a local radius of ten miles. The chain was a family-run business owned by two local general practitioners. The son of one of the owners acted as general manager and visited each home every day to deliver fresh fruit and vegetables and sort out any problems for the staff. The home was situated within a culturally mixed, leafy residential area, two miles from the city centre.

Design and layout

A converted Victorian house provided the main communal areas including two lounges and a large dining room, with the kitchen located off the dining room. Most of the bedroom accommodation was laid out on two floors of an additional wing completed two years ago. A laundry and office were located on the ground floor of this extension. Residents' rooms had all been recently decorated in an individual style and residents had been involved in choosing the decorations wherever their cognitive ability allowed. Although individual rooms were not large, all had en-suite facilities. There were two double rooms and these were much larger.

Outside, an enclosed courtyard allowed residents with dementia the opportunity to go outside in relative safety. The courtyard also housed a washing line and washing blowing on the line created a strong impression of domesticity. The environment was very homely and comfortable with net curtains and lots of ornaments furnishing surfaces - very typical of a normal family home. The main lounge had a very large window overlooking the street and this had a quarter net curtain so that residents' view of the road and passers-by was unrestricted. Two toilets were situated within a few yards of the communal rooms enabling easy access.

Pattern of the day

Day staff arrived at 07.45 and a handover report was given by the night RGN to all staff, usually sitting around a table in the dining room with a cup of tea. A notable feature of this home was that carers were fully involved in discussion about individual residents and frequently offered their own observations and suggestions. All staff were then involved in helping residents to get up, washed and dressed, working in pairs. Carers made a point of trying to work with their own designated residents each day. The staff seemed very familiar with each resident's preferred routine but offered flexibility in relation to time for getting up on a daily basis. Once each resident was dressed they were escorted to the dining room and the cook prepared breakfast as they arrived. A wide choice was offered and again the

staff were extremely flexible as the following extract from my fieldnotes illustrates:

Drew, the cook's assistant was making breakfast and is able to offer almost anything they want including a full cooked breakfast. One resident said he didn't want his porridge, in spite of having asked for it and the requested egg sandwich was brought almost immediately. The atmosphere was extremely relaxed.

Once those residents needing two helpers were up and dressed, the RGN began to give out medications. These were pre-distributed in *dosette* boxes by a local pharmacy. The RGN generally took time to speak with individual residents while administering medications. The nurse manager arrived at 09.00 and spent some time in the dining room speaking with individual residents. She would help with any residents who still needed to get up before starting on phone calls and paperwork.

After breakfast residents chose either to remain in the dining room or to sit in either the music or television lounge. The music lounge usually had music on the stereo and a selection of tapes and compact discs were changed regularly during the day. Residents seemed to appreciate the music, often singing along and sometimes requesting that a particular tape be put on. The music also provided a talking point.

Once all residents were up and had had breakfast, staff took a break together. Over tea and a large plate of toast, the conversation most commonly centred on events within the home. Residents would frequently join them and this could have posed a threat to confidentiality if the staff had not been so sensitive, switching from any delicate topic of conversation if residents or relatives came within earshot. Occasionally, residents were discussed with other residents and relatives but this was very much in the context of a supportive community of people who knew each other well and cared about each other.

Coffee or tea and biscuits was served by the carers and then residents were helped to the toilet and escorted into the dining room for lunch. Tables were usually laid by one of the residents. The menu for each meal was displayed on a white board in the dining room and the cook operated a six-weekly rolling menu which was adapted according to seasonal availability. Meals were served one table at a time and the proximity of the kitchen to the dining room ensured that food was hot and freshly served. Lunch was a highlight of the day and residents seemed to enjoy the food very much. All staff were engaged in helping residents to eat if necessary and facilitating social conversation at each table. Visitors were also actively engaged and offered a meal.

Activities tended to take place in the afternoon: sometimes a concert, and regular trips into the countryside with residents and staff participating on a rota basis. The newly appointed activities co-ordinator had revived an interest in board games among the residents and during the period of observation a craze for dominoes and ludo was in full swing. When there were no specific activities, carers and qualified staff spent time in the lounges, engaging residents in conversation:

Alison (deputy matron) came in and sat down and said to Mary 'Well what do you know then? She then initiated a conversation about all the changes that are taking place in the city centre and encouraged Mary to talk about her memories of what it used to be like. She gradually drew in different residents until a group of six were having quite a lively discussion.

Afternoon tea was served at about 3.00pm and tea at 5.00pm. On occasion residents were offered a choice of having their tea on their laps and this introduced some variety into the routine. One evening fish and chips were ordered and were eaten directly from the paper. 'Treats' like this also broke up the routine.

After tea, some residents were bathed and returned to the lounge in their night-clothes and dressing-gowns. I wondered whether this was appropriate given that there were both male and female residents and often visitors in the lounge during

the evening. However, everyone I spoke with seemed very happy with this arrangement. Very few residents were helped to bed before the night staff arrived at 19.45. Everyone joined in the handover report before the day staff left at 20.15. Residents were often still in the lounge chatting with staff at 10.00pm.

Residents' experiences of care and relationships

Most residents who could express an opinion, while they would have preferred to be in their own homes, were happy to be living here and felt the staff were 'marvellous', 'wonderful' and 'would do anything for you'. Residents liked their rooms and generally found the home very comfortable. Some residents had developed very close relationships with other residents and obviously looked out for each other. One lady and gentleman for example had formed a close friendship since admission and always sat next to each other in the small lounge, often holding hands. They also dined together. Staff were sensitive to these relationships and ensured that residents were kept informed, for example if a resident was ill and remaining in their room.

Contact with their families was highly valued:

"It keeps me in touch with what's going on. My daughter brings me in all the papers and she catches me up on all the gossip. She's very good to me."

Relationships with individual members of staff were also important and residents spoke warmly of individual members of staff in their absence.

"Martin, he cheers me up. He comes in and he always gives me a cuddle and a kiss. He's special."

The consequences for residents of members of staff knowing their day to day routine were apparent in many ways. The following field-note described one example:

The importance of continuity of care was obvious today in the way that Debbie was with Sally. She is obviously a highly skilled carer and she knows what Sally's likes and dislikes are. During her bath she was also able to talk with her about their trip out to Bakewell on Monday, reminiscing about their shared experiences. She was gentle and kind throughout, even though Sally was occasionally quite rude back to her.

The layout of the home meant that it was much easier for residents to contribute to daily tasks within the home, for example laying the table or peeling vegetables. The proximity of the dining room to the kitchen also meant that residents could take part in activities such as baking.

Experiences of care and relationships for relatives

Without exception, all the relatives who contributed their views said they were extremely happy with the care at Nursing Home C. People spoke particularly of the homely feel and said this was what they had wanted for their relative - a place that felt like a home. The small size and welcoming feel had contributed to the choice of home for many relatives. Most visitors spent time with their relative in the communal areas, although they were also encouraged to take them to their room if they wished. There was lots of interaction between staff, relatives and residents and relatives frequently engaged each other in conversation.

A relatives committee had recently been established by the new manager and two meetings took place during the period of observation. Although attendance at these meetings was low (four relatives at the first meeting and seven at the second), nonetheless those present were enthusiastic about the opportunity to meet together with senior staff and discuss any concerns. They also described how the group had a supportive function. At both meetings, relatives were invited to raise any issues about which they were concerned but nobody present at the observed meetings seemed to have any particular worries. Refreshments were provided and both relatives and staff seemed to enjoy the time together. At both meetings participants discussed ways of involving more relatives in the future and a regular

newsletter was suggested which could summarise the discussion at each meeting and be available for those who were unable to attend. This was duly produced. Opportunities for fund-raising were also discussed. The following field-note gives a 'flavour' of the meetings:

Marge had a very loose agenda, mainly around issues to do with the Spring Fayre, although this wasn't planned in detail and I was left wondering how well organised things would be. Alan and his father attended and his dad kept butting in with things about his life with Daisy which weren't really relevant to the discussion but the group were sympathetic and supportive and listened attentively. He mentioned a book that is available in the local library 'Porn Shop on a Monday' which documents the life of local residents and apparently Daisy is featured. This led into a discussion about the potential value of biographical work with residents and I mentioned a project currently ongoing within the University to develop this approach. The relatives seemed quite interested, although there was acknowledgement that this would need to be negotiated with individual residents. I said I would find out more about the project. Beryl provided delicious snacks, and drinks including wine or beer were offered.

Outside of the meetings, there was evidence that relatives felt comfortable about raising any concerns with the staff. For example the daughter of one resident was observed talking with two carers about the fact that some of her mother's clothes had gone missing:

The carers appeared to take this very seriously and one wrote down a list of the missing items. The daughter was also explaining that she liked to wash her mother's skirts and tops herself because they tend to spoil in the home's tumble dryers. Within ten minutes one of the carers was discussing this with the laundry assistant and brought her back to speak with the daughter. This was a very good

natured discussion and although the daughter was essentially making a complaint it was received very well by the carers and she seemed comfortable discussing these issues.

All staff seemed to make a point of supporting visitors, particularly those who visited regularly, looking for opportunities to join in with their conversations.

The views of one wife whose husband had been living at the home for twelve months were typical:

“I liked that it was small and homely and it felt very welcoming. Now it feels like they are family. All the residents get a bit of love - there are no favourites. I look forward to coming here - it gives a bit of structure to my day. I catch the bus about eleven and I’m here to help Will with his lunch. They always offer me a meal, although I usually just have a cup of tea. They’re like my family.”

Staff experiences and relationships

All staff, with the exception of the nurse manager, worked long shifts from 07.45 - 20.15. Staff worked in teams and generally worked three consecutive days one week and four consecutive days the next. Although these shifts were obviously tiring, all staff said they preferred working this pattern because of the continuity that it provided for residents and for the extended periods of time off. Some of the carers talked about how the home felt like a second home to them, partly because they spent such lengthy periods of time there but largely because of the informal atmosphere and the loving relationships they had built up with the residents. Two of the carers told me how they missed the residents during their days off and sometimes rang the home to find out how they were if someone was particularly poorly. Staff were also regularly observed at the home during time off, particularly for social events.

There was lots of information sharing between staff and clinical problems were discussed with staff at all levels. For example, one long-term resident who was in

the terminal stages of her illness had been prescribed oral diamorphine for pain relief.

Betty said 'Our main concern is that she should be free from pain'. However there was obviously some anxiety about starting her on a potentially addictive drug that could hasten her death. Betty and Marion were careful to check with the qualified staff that they were happy to administer the drug and also discussed the implications with the carers.

Staff appeared to feel well supported by the owners of the home and relationships with the general manager were relaxed and informal. The general manager was a regular sight around the home and seemed to make a point of chatting with residents and relatives during each visit. In an interview, he suggested that the calibre of the staff was the most important factor in ensuring high standards of care. He also felt that the style of management was important in making staff feel valued and hence encouraging them to stay. There was no set budget for the home, rather if the staff made a case for something he would normally agree and this was confirmed by the qualified nursing staff.

"They can have anything they want - we don't give them a fixed budget. They may have to wait for it but they can usually have it in the end. I don't mind what they buy as long as its used."

In contrast to the supportive management style of the home's owners, the nurse manager found the approach of the local registration and inspection team less helpful:

Spoke with Marge. She was upset by an unannounced visit of the registration officers last week. They said it wasn't an inspection visit, but they asked the staff lots of questions including whether she was involved with residents' care. They were also concerned at the apparent lack of activities for residents. She had explained that

they in the process of appointing a new activities organiser, but the incident upset her deeply. She obviously feels that they do not appreciate the effort she is putting in.

This incident revealed the importance of positive feedback at all levels within the organisation if staff are to feel valued.

Summary: Impressions of Nursing Home C

My overwhelming and recurrent impressions of this home were of a lively community, a home from home. The pattern of the day and the organisation of care mirrored a domestic environment more closely than at the other case study sites, particularly in relation to choices offered to residents and flexibility in the day-to-day routine. Close and affectionate relationships between staff, residents and relatives ensured a sense of belonging and commitment for everyone with a stake in the home. This was due in part to the smaller size of the home which encouraged close relationships to develop. However, there were other factors at play. Effective and enabling leadership coupled with consistent staffing patterns resulted in a strong sense of teamwork and this ensured that staff were mutually supportive. Qualified staff were all registered mental nurses and it is possible that this focused training encourages practitioners to be more alert to the social and emotional needs of residents and their families.

Relatives were actively encouraged to be involved in the life of the home, although this was never forced. Staff sought opportunities to engage visitors in conversation and also spent time with them on their own and appeared to be very responsive if a relative had a particular concern to discuss. There was a strong sense of the home as everyone's home, a vibrant community with lots of laughter. This was encapsulated in the Spring Fayre which took place on the final day of observation

The Spring Fayre was a truly collaborative event involving staff, residents and relatives, with relatives taking the lead and setting up and manning most of the stalls. Bagfuls of gifts, produce and bric a

brac had been arriving for weeks.. A beautiful Spring day ensured a good turnout and everyone seemed to contribute: Doris reading palms for 20p, Victor manning the bookstall, Ediths neice and her husband manning the bottle stall, Val's friend on the tombola, Debbie making hot pork sandwiches in the 'café'. Those family members who weren't manning stalls came anyway and ensured that their relative secured a bargain. An ad in the local newsletter motivated members of the public to come along too and residents of another nursing home round the corner came along for a visit, escorted by staff and their own relatives. A great time was had by all and four hundred and thirty-five pounds was raised for the residents' fund. The sense of 'community' was palpable.

Cross case-analysis

In comparing and constrasting the case study reports, I was attempting to identify possible explanations for the range of experiences described by relatives within the Phase I interviews. From the factors considered within the context of each case study, the key values and objectives in operation within each home could be inferred. Collectively, these factors define the dominant model or culture of care which was different for the three homes within the study. While the culture of care in operation may not be explicitly recognised by staff, it is nevertheless a major factor in determining the experience of care for both residents and their relatives. It was quickly apparent that relatives' experiences within each home to a greater or lesser extent reflected the continuum of experiences described by the relatives in Phase I of the study. Furthermore the experiences of care described by relatives mirrored many of the experiences described by residents and by staff. Findings of the cross case analysis will therefore be framed using the five continua to compare and contrast the three case study sites. Potential explanations for these experiences will then be considered in terms of the model and culture of care in operation within each home. At this stage in the analysis, it began to emerge that one dimension in particular, that of working together or working apart, was especially significant in influencing experiences and to some extent determined

experiences in relation to the other continua. In other words, the creation of effective partnerships enabled both residents and staff to feel 'in control', 'in the know' and 'well supported', as well as reducing external pressures. This continuum will therefore be considered first.

Working together / working apart The key to 'working together' and to ensuring that the needs of all 'stakeholders' were met appears to be effective communication. Interviews carried out during Phase I of the project suggested that communication between relatives and staff and between staff members exerted a major influence on whether they felt staff were 'in tune' with their hopes for their relative and their care. Assessment and care planning involving older residents and family members and clear designation of responsibilities for care were also influential in creating the perception that residents' needs were met. The cross case analysis of data emerging from the case study sites confirmed the importance of ongoing assessment and effective communication in contributing to a sense of working together with staff, resulting in positive experiences for both relatives and residents. Indeed subtle differences were noted in the nature of interactions between staff and visitors at the three homes.

At Nursing Home A, it was quite possible for visitors to have no contact with staff at all unless they deliberately sought them out. Most of the interactions observed during the observation period took place around the nurse's office, most frequently with staff sitting in the office and the visitor or relative speaking from the doorway. This did not encourage lengthy communication or discussion of private or sensitive information. Some relatives were obviously perceived as trouble-makers, while others were perceived more positively. There was evidence to suggest that staff remained unaware of the needs of relatives, both at the time of admission to the nursing home and subsequently. During hand-over reports, relatives' desire to remain fully involved in decisions about the older person's care was, at times, questioned. In general, staff appeared to feel that they held 'authority' over decisions about residents. Care assistants were rarely observed interacting with visitors to the home.

At Nursing Home B, the majority of relatives were treated like respected guests and staff were always welcoming. Visitors had to pass by, or close to, the nurses' station in order to make their way to a resident's room or to the lounge areas and so qualified staff were usually aware that they were in the building. This also enabled visitors to request information about their relative's condition and sometimes information was volunteered spontaneously as the visitor passed by. Most visits took place in residents' rooms which were large and spacious, but this had the effect of limiting interaction between staff and visitors, with staff being reluctant to go into individual rooms during visits for fear of invading their privacy. A small minority of relatives who were regular visitors sought out the staff more frequently and made a deliberate effort to get to know them.

Because most visitors to Nursing Home C spent their time in the communal areas of the home, interactions with staff and with other residents and visitors were much more frequent. While it was perfectly acceptable for residents to take visitors to their room for added privacy this was rarely observed. More commonly visitors would choose to sit with their relative at one of the tables in the spacious dining room which became an all-purpose room outside of mealtimes. The lack of opportunity to share time with staff in communal areas at homes A and B might contribute to a sense of isolation for relatives. While the privacy afforded by being left alone may be welcome, relatives who find visiting a strain in terms of communicating with the older person may miss the opportunity to engage in conversation with others.

The case studies therefore suggested that the nature of the built environment and the use which is made of different areas within the home has an important impact on patterns of communication and on the way in which relationships develop. In particular it appears that the use to which communal areas are put can either encourage or inhibit social interaction. The confusing layout of Nursing Home A and distance of communal areas from staff offices seemed to discourage communication between staff and visitors. Lack of seating in communal areas had the effect of prompting visitors to take their relative to their room for the duration of their visit, limiting opportunities for interacting with staff. Alternatively, they

felt uncomfortable within communal areas and this did not encourage them to extend their visits.

Nursing Home B had a much more straightforward layout, identical on both floors. Communal areas were located centrally and close to the nurses' station. Residents' rooms were situated along either side of two corridors extending from this central area. Here the lounges were large and roomy but were used infrequently, with most residents preferring to stay in their rooms during the day. Reasons for this are unclear but may be concerned with a lack of staff presence in these areas or, as suggested by staff, the greater desire for privacy of these residents. The exception was the small smoking lounge where a few residents and regular visitors congregated from time to time. Again, contact between staff and relatives was often limited to a welcome on arrival unless the relative specifically sought contact.

Nursing Home C also had a central area with a large dining room and sitting area off to one side and two separate lounges all leading off a central corridor. The difference here was that the majority of residents chose to spend most of their day in this central area, only returning to their own room at night. Hence visitors also congregated here. This facilitated interaction between visitors and staff as well as between visitors and other residents and their relatives. In particular the large dining area was used for sitting and conversing between meal times and most staff chose to take their breaks here.

In all three homes, a good deal of affection was demonstrated between staff and residents: however, in Nursing Home A, this was selective, with certain residents being singled out for attention and others seeming to be actively disliked by some members of staff. Nursing Home C was the only home where there did not appear to be 'unpopular' residents and all residents were treated with equal respect and affection. The sense of treating residents as 'family' was present among individual members of staff at all three homes but was most prevalent at Nursing Home C. This acceptance and affection for all residents is likely to have

contributed to a sense for relatives that they were working together to ensure best care for the older person.

Surprisingly, examination of residents' care-plans and records provided little indication of the extent to which staff relatives and residents worked in partnership. Examination of records at all three case study sites revealed very little information about contacts with relatives. While care plans were reasonably comprehensive in relation to residents' physical needs and problems, they were less explicit in relation to social and emotional needs. Furthermore, care-planning documentation provided little evidence that goals of care had been negotiated with residents and/or their relatives.

The extent to which family caregivers were engaged in assessment of the older person's needs and planning of care at the time of admission appeared to vary between the three homes. During the period of observation at Nursing Home A, several 'crisis' admissions were observed with the older person arriving during a busy period at the nursing home, often unaccompanied. Consequently, it was sometimes several hours before a qualified nurse could spend any time with the older person. Here, completion of the assessment documentation was carried out either at the nurses' station or in the nurses' office away from the direct involvement of the older person and any family members. Contact with the older person at this time seemed to focus largely around documenting property and personal belongings rather than an assessment of need. At the other case study sites, senior managers suggested that the process of assessment was completed over several days as the staff gradually got to know the resident. There appeared to be some attempts to engage relatives in the assessment process, but the small number of admissions during the period of observation limited the extent to which this could be observed in practice.

The extent to which staff members are able to work effectively together to meet the needs of residents also has implications for the experiences of residents and their relatives. At Nursing Home A, relationships between staff were acknowledged to be hierarchical and, at times, adversarial, and the nurse manager

spoke of the difficulties she was experiencing in motivating the carers to meet the standards which she felt were appropriate. There were also 'cliques' among the carers and some hostility between individual members of staff. A hierarchical arrangement where selected carers who had achieved NVQ Level 3 were appointed as senior carers was unpopular with many of the junior staff and was mentioned repeatedly as a 'bone of contention'.

At Nursing Home B, relationships between staff members were generally friendly and mutually supportive, although obviously hierarchical. There was for example little obvious involvement in the direct physical care of residents which was left largely to the care assistants. At Nursing Home C, relationships between staff were generally acknowledged to be good with a strong sense of teamwork. The nurse manager repeatedly praised her staff and gave them the credit for standards of care within the home. The qualified staff here also appeared to have more autonomy and felt well supported by the owners and manager.

Being in control / losing control The degree to which staff, relatives and resident created partnerships in care appeared to be an important factor influencing the extent to which residents and relatives retained a sense of 'being in control'. The nature of close relatives' experiences of the admission of a loved one to a care home will inevitably be shaped and influenced by the nature of the relationships which both they, and the older person, are able to develop with staff. Again the case study observations revealed subtle differences in staff/resident relationships within the three homes, particularly in relation to the exercise of power and control demonstrated within interpersonal communications. At Nursing Home A, many residents felt that they had no choice but to fit in with the routine of the home and this was certainly supported by observations of routine practices such as weekly bathing. On occasion, residents were taken loudly voicing their disapproval to the shower room and continued to protest throughout the procedure with little response from members of staff. At Nursing Home B, the daily routine was certainly more flexible, but many residents felt that staff did not spend time with them, just 'chatting'. The high turnover among carers who provided the majority

of day to day care, meant that residents found it difficult to build relationships with individual members of staff, or risked being upset when they left the home.

At Nursing Home C staff seemed much more aware of the individual likes and dislikes of different residents and care was more orientated to meeting individual needs. Staff turnover was much lower and the ratio of qualified staff to carers was higher. Qualified staff were more involved in day to day care of residents and were able to role model appropriate interactions and behaviours to carers. Even though residents here were more cognitively impaired than at Homes A and B staff went to great lengths to ensure that they were able to exercise choice in relation to their day to day routine whenever possible. Relatives were also fully involved and seemed more able to retain ownership of decisions.

The extent to which staff felt 'in control' also varied between the three homes. Senior staff at Nursing Home A were constrained by lack of access to resources, even for some essential items of equipment. There was effectively no budget for staff training and education. The proprietor was something of a distant figure who visited the home occasionally but delegated routine management to an administrator. Neither of these individuals played much of a part in the day to day life of the home but nonetheless seemed to control access to resources quite fiercely. As mentioned previously, junior nursing staff and care assistants at this home seemed to feel powerless to make any changes to the daily regime.

At Nursing Home B, the clinical nurse manager and business manager enjoyed a degree of autonomy in relation to some practices within the home, particularly clinical matters. The home was well equipped and a rolling programme of in-service education could be accessed by any member of staff. However, these sessions focused largely on health and safety issues and on policies within the home rather than the development of practice. There were obviously some areas where the managers felt constrained by the 'corporate culture' of the parent company. For example, targets for bed occupancy, incentive schemes and budgets were all determined externally. Nonetheless there was a lot more evidence here of staff acting on their own initiative to improve experiences within the home. At

Nursing Home C, staff were in daily contact with the son of the proprietor, who acted as general manager, and were able to make a case for additional resources which were rarely denied. The proprietor trusted his staff and obviously perceived that they were the experts in relation to residents' needs. Because of the close relationships that had developed between members of staff of all grades and roles, everyone seemed to feel that their opinion mattered and that they could influence what went on in the home. This was apparent in the often lively discussions during handover reports and during breaks. Because staff felt valued, they also felt that their opinions would be taken into account. Similarly, senior staff were careful to keep junior staff informed of decisions in relation to the care of individual residents and check their understanding and viewpoint. The extent to which staff felt that they were in control of events, or not, was also a function of the degree of pressure experienced within the home.

Feeling under pressure / no pressure The main pressures for staff arose from staff shortages and the complexity of residents' needs. Staffing levels varied between the three homes and were difficult to compare due to the different numbers of places within the homes and variations in occupancy at the time of the observation period. Shift patterns also varied, with staff at Homes B and C working twelve hour shifts. At Nursing Home A, there was usually one qualified member of staff and seven or eight care assistants providing care for the forty-four residents on the upper two floors during the morning shift. The nursing home manager was supernumerary to these figures for two out of five shifts per week. At Nursing Home B, the figures were: one qualified nurse and five care assistants for thirty residents. Once again, the nurse manager was supernumerary for three of five shifts, and the business manager worked on a full-time basis. At Nursing Home C, one qualified nurse and three care assistants provided care for twenty-four residents with the nurse manager supernumerary. The input of activity coordinators at each home was additional to these staffing levels. Overall, Nursing Home C had a slightly better qualified nurse to resident ratio than the other two homes. There certainly appeared to be a reduced sense of 'being under pressure'

at Nursing Home C but all staff at all homes felt that the single thing which would improve the experience of residents and relatives was having more staff.

The rigidity of daily routines within the home was an important factor in determining the extent to which relatives felt under pressure. To some extent a fixed routine can facilitate the processes of visiting and supporting a family living in a care home as relatives know what to expect. However, if routines are so rigidly adhered to that individual preferences cannot be accommodated, this is likely to prevent relatives from being able to continue their relationship with the older person in the way they would wish. The degree to which routines dominated day-to-day experiences varied between the three homes. Although a clear routine was in operation at all three homes, and to some extent was obviously valued by residents and relatives, there appeared to be more flexibility in relation to individual choices at Nursing Home C. There also appeared to be a greater willingness to negotiate a relative's level and type of involvement so that relatives were not under pressure to participate in ways with which they felt uncomfortable.

Working in the dark / being in the know The extent to which relatives, residents and staff had access to relevant information, and were able to develop appropriate skills to contribute to the community were also important factors influencing individual experiences. Relatives interviewed in Phase I of the study were very conscious of the contribution of staff preparation and training to standards of care. This was reflected in concerns about skill-mix and the lack of training for care assistants. Within the case studies, the contribution of qualified nursing staff to direct patient care also emerged as an important influence on the care practices of unqualified staff. In nursing homes A and B for example, the role of the qualified nursing staff appeared to be largely managerial: during each shift, a fair amount of the qualified nurse's time was taken up with completing paperwork and liaising with people outside the home. The main clinical tasks involved wound dressings and the administration of medication. Care assistants appeared to meet most of the direct care needs of residents and worked largely without direct supervision. Qualified staff encouraged care assistants to undertake the NVQ level two and three programmes, but at Nursing Home A, the fact that staff had to pay the fee for

this themselves acted as a disincentive. The NVQ programmes involve supervision and assessment with some theoretical sessions; however, these were structured largely around activities of daily living and there appeared to be little emphasis on psychosocial aspects of care.

Nursing Home B had an operational manager (who was not a nurse) and a clinical nurse manager. The clinical nurse manager worked on the floor for some of her shifts but others were spent largely in the office completing paperwork and recruiting staff. The qualified nurse on each floor spent most of the shift sitting at the nurses' station, ostensibly co-ordinating the shift, although little direction and communication with carers was observed. At both homes A and B the qualified staff appeared to give very little direction to carers. Handover reports were brief to the point of being perfunctory and carers rarely seemed fully engaged in the report. The nurse manager at Nursing Home B suggested that it would be inappropriate for care assistants to have access to detailed information about residents nursing needs and social circumstances and revealed that some relatives had actually complained that such information had been shared with care assistants. An in-house rolling programme of education at Nursing Home B focused mainly upon health and safety issues and *customer care* policies. To some extent, relationships followed a corporate model, with grades of staff being aware of their responsibilities and with little interaction or discussion about working practices taking place. Directives were awaited 'from above' and employees at the level of the home felt they could only operate within corporately defined limits.

At Nursing Home C the qualified nurse on a shift and the nurse manager both appeared to have much more direct contact with residents and visitors to the home. Again, this was partly due to the layout of the home which meant that all activities took place in reasonably close proximity. However, it was the only home where qualified staff were observed to be regularly involved in helping residents to get up in the morning and bathing residents, providing opportunities for role-modelling care to more junior members of staff. Handover reports were detailed and all staff were actively engaged, with carers contributing their knowledge of individual residents and making suggestions. Furthermore, unofficial breaks were

often spent discussing the needs of individual residents and relatives. These breaks also provided opportunities for informal teaching sessions.

Relatives interviewed in Phase I of the study had also suggested that continuity of care and carer were important factors in determining whether staff were 'in the know' in terms of being aware of the individuality of an older resident and their significant others. At the time of data collection, Nursing Home A did not operate a system of named nursing whereby the assessment of care needs and planning and evaluation of care is the individual responsibility of a qualified, named nurse. Such a system was in operation at homes B and C. At Nursing Home B, the nurse manager also acted as named nurse to designated residents: this was not the case at Nursing Home C. Key-worker systems where residents are allocated to a named care assistant were in operation at all three homes. However, the tasks of the key-worker related mainly to overseeing care of the resident's laundry and ensuring that their room was tidy. Only the key workers in Nursing Home C appeared to possess in depth biographical knowledge of residents to whom they were allocated.

Access to information about a resident's previous life and family relationships varied to some extent between the three homes but overall was limited. At Nursing Home B, a social history assessment which sought more detailed information about a resident's past life and family relationships was discontinued because it was felt by staff to be too intrusive. Very little information was included in residents' notes or care plan about their life prior to admission and knowledge seemed to be passed on by word of mouth.

There is an obvious tension between providing access to sufficient information about the older person to facilitate continuity of care and protecting the older person's right to privacy. However, written information could be developed in partnership with the older person, and where appropriate their family, and this could remain in the possession of the older person. Staff could then ask permission to view the document as appropriate. Such a scheme was under consideration at Nursing Home C but had been actively rejected at Nursing Home

A due to lack of time and at Nursing Home B because of threats to residents' privacy.

Feeling supported / feeling unsupported Many of the factors which contributed to relatives, residents and staff feeling supported have already been discussed. In particular, where staff and relatives were able to create effective partnerships, then this usually resulted in mutual support and comfort. At Nursing Home C for example, regular contact between staff and relatives enabled relationships to develop, which in turn meant that staff were more 'in tune' with relatives' needs. They were therefore able to respond quickly to any signs of anxiety or distress. However, this worked both ways, with relatives themselves being sensitive to situations where staff were obviously under pressure and being prepared to modify their own expectations or offer practical support. At Nursing Home A on the other hand, where there was little contact between relative and staff, relatives' obvious needs for support often went unnoticed. Similarly, relatives often seemed unaware of the various pressures on staff and consequently were less likely to be sympathetic and more likely to complain.

In the course of considering the experiences of residents, relatives and staff across the three case study sites, patterns began to emerge. These patterns identified structural characteristics and care practices which contributed to experiences of continuing care, and began to suggest the values and beliefs underpinning such practices. These will now be summarised and considered within the context of recent literature in an attempt to move towards an explanation for the wide variation in experiences encountered during both phases of the study.

Summary and synthesis

At the start of the 1990's Kahana and Young (1990) argued that the challenge for the future of caregiving research was to move beyond the static and largely unidirectional models that then existed and to take account of the dynamic and interactive components of care. This, they suggested, would involve a

consideration of the perspectives of all the major players to include the family carer, care recipient, and where appropriate, professional or paid carers.

Although their analysis was concerned primarily with care within the community a similar logic could apply to residential or nursing home care where the interactions between individuals are potentially even more subtle and the power relationships even more diffuse and blurred. To add a further layer of complexity Davies (1998) contends that there are three 'caring' perspectives which need to be taken into account: **caregiving** which refers to care that occurs between family and friends on an unpaid basis; **carework** which relates to paid care given by unqualified staff; and **professional care** which relates to care given by qualified and trained personnel. The nursing home environment provides a microcosm of the interactions and tensions that exist between these three facets of care and the effects that these interactions have on the quality of care experienced by those giving and receiving it.

In terms of quality of care Brechin (1998) provides a cogent argument which asserts that whilst care is a process, it is primarily about relationships, and any account of the experience which fails to consider these relationships will 'only reveal part of the story'. There are clear similarities between this position and that of Kahana and Young (1990) and as Brechin (1998) contends:

'If we want to understand 'good care' in the sense of care which brings positive consequences for those who are involved, then we must take account of the person and the relationships itself and not just see care as an instrumental means to an end.'

(Brechin 1998 p177)

This, according to Brechin (1998), means that any analysis of care must address the experiences of all those involved so as to tease out the tensions and pressures which militate against good care in order to help identify and build appropriate support structures. Brechin believes that care can only be seen as 'good' if it is good from the perspectives of all parties involved. This, she contends, requires a construction of care which recognises and acknowledges different perspectives but

which is underpinned by relationships based on mutual respect and a sense of equality.

'To arrive at this possibly more sophisticated position requires a process which could be understood as a process of deconstructing rather than denying or ignoring difference. The concept of 'equal people', for example, does not deny real differences exist however difficult they may be to define. Rather it brings to the foreground commonalities of humanity, shared aims and wishes, human needs and human rights: an entitlement to ordinary human pleasure and lifestyle.'

(Brechin 1998 p184)

It is just this sort of 'possibly more sophisticated position' that is sought here. The data from the case studies provide some indications of the procedural, structural and resource factors that may serve either to enable or to limit the opportunities for staff and relatives to engage in mutually reinforcing interactions. It is also possible to infer some of the important values and care objectives which underpin these characteristics and these core values start to suggest and define the nature of the community which is created. An attempt at representing the most significant dimensions of each type of community is included as Table 5.2. After Stanley and Reed (1999), the table represents an attempt to disentangle the models in terms of their key characteristics. However, this form of presentation runs the risk of under-representing the subtlety of these models and the way in which they coexist, intertwine and provide counterpoints to each other within a single organisation (Stanley and Reed 1999). It is important to reiterate that all of these models may be influencing practice within a single care home. The value of presenting them in this way is that:

'...we can make some more open and reflective choices about the way we want practice to go, rather than be caught up in the momentum of a set of ideas that no-one has articulated or challenged.'

(Stanley and Reed 1999 p73)

Elements of these models have been described elsewhere (see for example Townsend 1962, Miller and Gwynne 1972, McDerment et al 1997, Stanley and Reed 1999): however, these accounts have tended to focus upon the experiences of residents rather than a consideration of the ways in which the values, expectations and perceptions of all the main stakeholders inter-relate to create a 'culture of care'. It is hoped that by considering the nature of these inter-relationships, previous analyses may be extended to begin to suggest the most appropriate model for supporting frail older people and their families. The key characteristics of each type of community will now be described.

Table 5.2 A typology of types of community within care homes

CHARACTERISTICS	TYPE OF COMMUNITY		
	Controlled community	Cosmetic community	Complete community
Practice as:	Control	Service	Enablement Nurture
Objectives	Maintenance	Customer satisfaction Profit	Growth and development Partnership
Important values	Minimising risk Maintaining the status quo	Quality Privacy	Well-being Inter-dependence
Organisation of work	Task-centred Routine	Customer-centred Individual	Person-centred Relational
Relationships between staff and residents	Authoritarian Favouritism	Attendance	Reciprocal
Relationships between residents	Fellow captives Competitive	Fellow guests Reserved Critical	Family Intimate
Relationships between staff	Hierarchical Segregation of roles Occasionally hostile	Hierarchical Corporate	Collegial Blurring of roles
Relationships between staff and relatives	Distant Sometimes combative	Stage-managed Cordial but superficial	Natural Spontaneous Equal Affectionate
Quality as	'Good geriatric care'	'The satisfied customer'	'Community of equals'

Controlled community The 'controlled community' reflects many of the characteristics of the 'warehouse' model first described so vividly by Miller and Gwynne in 1972. Safety and containment are prime objectives within this model, often at the expense of personal autonomy. Care is characterised by the operation of a standardised series of task-centred activities with some evidence of personalised care, but within a pervasive routine. Work scheduling is orientated to 'getting through' a series of tasks, most of which have to do with meeting the basic physical necessities of life rather than residents' social and emotional needs. Minimising physical risks to residents is an important value and is prioritised above autonomy and personal growth. Relationships between staff and residents are characterised by power and authority with staff having strong likes and dislikes for individual residents. This, in turn results in competition between residents for staff approval. However, it can also result in strong positive relationships between residents as they realise that they are 'in this together'. Staff often lack the necessary skills to maintain a positive culture and have lost confidence in the capacity of the institution to change (Stanley and Reed 1999). Staff relationships are hierarchical, critical and sometimes punitive. Relatives are perceived as visitors and outsiders, sometimes interfering in that they constitute a threat to the objectives of the institution. The model is legitimised by the perception that residents lack the ability for self-control and therefore this needs to be provided by an external agency. The views and preferences of service users are secondary to the institutional view of what should happen. This model often reflects an isolated community with only tenuous links with the outside world.

The '*cosmetic community*' is similar to the tariff model described by McDerment et al (1997). This model is derived from contemporary service industries such as hotel and travel services. Its focus is individual rather than communal and it seeks to satisfy individual needs according to means. Privacy for service users is highly valued, but this may be at the expense of facilitating meaningful relationships, which tend to be reserved. Residents are generally less tolerant of each other, and of what they perceive to be inadequacies on the part of the staff and complaints are an accepted feature. Staff relationships with relatives can be influenced by expressed expectations but are otherwise cordial but superficial. The cosmetic

model reflects the business culture that has developed in the care industry, which emphasises service specifications and the need to demonstrate concrete, measurable services and outcomes. However, the model may be divisive since some residents may be excluded on the basis of cost. The language of 'customer care' may also have implications for the 'homely and welcoming' atmosphere so valued by residents and relatives alike. Nonetheless, the cosmetic community is likely to appeal to some older people and their families, particularly since it is predicated on the illusion of the 'customer' retaining control.

The '*complete community*' in contrast is relationship-based and community focused. Care is orientated towards enabling and nurturing residents to achieve their optimal quality of life and is person-centred. Relationships between residents and staff aim to empower residents and afford them as much control as possible, but also results in benefits for staff. These relationships are affectionate and mutually reinforcing. Relationships with relatives and other community dwellers are fostered and encouraged due to the mutual benefit that such relationships can afford. Roles within the home are interchangeable to a degree and everyone feels that they have a voice. Relationships between staff are mutually supportive and reciprocal. Effective leadership is key to the achievement of the complete community and this involves ensuring that staff are valued and supported. The result is a community of equals in which every member; resident, relative or staff, makes an important and recognised contribution.

It is important to recognise that the core values and objectives informing each of the community types, being more abstract than the practices and interactions which were observed in each of the homes, can only be inferred from those events and have not been confirmed by the participants in the case studies. Furthermore, features of each model were observed at each home within the actions and interactions of individual members of staff, and the three case study homes did not identify rigidly with one model. However, the predominant culture most in evidence at each home matched one of the three model types. It is possible that there are alternative types of community which were not apparent within the data gathered for this study. However, observations and interviews during the second

phase of the current research suggest that it is the 'complete community' model which is likely to result in the most positive experiences for older people and their relatives. This resonates too with the expectations and experiences described by relatives within Phase I of the study.

This typology of communities within care homes is at an early stage of development and requires further empirical testing and elaboration. Nonetheless, I feel that there is sufficient evidence within the case study data, supported by the interview findings, to suggest that the dominant model of care within a nursing home, whether implicit or explicit, has important consequences for the experiences of residents and their close relatives, as well as for the experiences of staff. The extent to which the typology described here, and the five continua of experience which emerged from the findings of Phase I, mirror co-existing findings within the literature is considered within the next chapter.

CHAPTER 6. SYNTHESIS OF FINDINGS AND DISCUSSION

Introduction

At the beginning of the 21st century, the care of frail older people continues to present one of the most significant challenges for health and welfare service providers. Furthermore, while community care remains a key policy direction throughout Europe, it is likely that a range of models of collective care will be needed by increasing numbers of older people. The original aim of this research was to develop a deeper understanding of the needs of relatives and family caregivers who help an older person to move into a nursing home, in order that nurses and other health care practitioners may be better prepared to meet those needs. I intended to explore the experiences of family caregivers in relation to helping a relative to move into a nursing home and continuing to support them within that setting, then to locate these experiences within an analysis of current practice within nursing homes. Within the study I considered the experiences of 37 close relatives of older people admitted to nursing homes in a large city in central north England. Eleven other close family members also took part in these interviews. I also report evidence from case study research in three nursing homes in the same locality. Data from both phases of the study indicate that the extent to which the needs of relatives for information and support are met, both around the time of admission and afterwards, varies widely. Further analysis of these data suggests a number of organisational and individual factors which appear to be associated with the ease of transition to a modified caring relationship for older people and their family caregivers.

Within this chapter I will attempt to summarise these factors and draw comparisons with existing literature, both that which is summarised in Chapter 2 of this thesis and literature which appeared during the period of data collection and analysis. This discussion is followed by a brief methodological critique of the substantive literature focusing upon relatives' experiences of nursing home entry

to date. An overview of the main theoretical perspectives, both substantive and formal, which inform this literature, is followed by a more detailed consideration of the nursing model of transitions described by Meleis *et al.* (2000). This mid-range theory has been developed on the basis of a wide range of empirical studies, but to my knowledge, its relevance to the experience of family caregivers in relation to the transition to a nursing home has not been explored. I will also provide a critique of this model and attempt to extend and modify the framework to reflect the findings of the current study more fully. But first, in order to set the discussion which follows in context, a critique of the methodology employed within the current study is presented.

Strengths and limitations of the study

It is essential to consider the findings of this research in the light of the limitations of the methods employed. As indicated in Chapter 3, the methodology was developed and refined throughout the study and it is true to say that the methodological approach outlined in Chapter 3 had not been articulated when data collection commenced, as fully as it subsequently was. To some extent, the constructivist perspective emerged as the most appropriate epistemological approach during the early period of data collection and analysis. It is likely therefore that early forays into the field were not as explicitly informed by this perspective as those taking place later in the study.

Sampling issues

Within both phases of the study, a purposive approach to the identification of research participants was adopted in an attempt to ensure that a range of experiences and perceptions were accessed. It could be argued that the sample of relatives interviewed during Phase I of the study was potentially open to bias as they were essentially either self-selected or selected by nursing home managers. It is conceivable that those recruited via advertisements in local newspapers may have been prompted by extreme experiences, either positive or negative. Similarly, nursing home managers may have identified relatives who they perceived would reflect positive images of the home. However the fact that a wide

range of experiences were described in the interviews suggests that this potential for bias was not realised. Furthermore, the sample reflected a range of caregiving relationships and social backgrounds and included relatives with experience of a range of nursing homes (32 homes in total). Importantly however, all of the participants were white and the findings cannot be assumed to reflect the experiences of family caregivers from ethnic minority groups.

While interview participants were encouraged to recount the background and history to their current situation, the interviews provided a snapshot picture and generated limited information about how a relative's experience of a particular home might alter over time. Follow-up contact through the interview summaries produced some response which suggests that relatives may modify their views of a particular nursing home over time, in particular by redefining their views of what constitutes 'best care' and modifying their expectations. Longitudinal study would add to this picture.

The time spent in each case study site was limited to between twelve and fifteen days over a six month period. Furthermore this was usually on one day each week so that it was not possible to gain an impression of the flow of activity within the home from one day to the next. While observational periods took place on different days of the week, including occasional weekends and extended from early morning into the evening, no observations were carried out during the night. Nonetheless I felt I was able to gain clear impressions of the different culture within each home and the way in which this influenced the experiences of residents and their relatives. Few new insights were emerging towards the end of the period of observation in each home.

Again, the case study nursing homes had very few residents from ethnic minority groups and the findings cannot be assumed to reflect universal experiences. This is obviously an area needing further research as the number of older people within ethnic minorities is growing rapidly (Blakemore and Boneham 1993).

Ethical issues

Some of the ethical issues raised by the observation of health and social care practice were discussed in Chapter 3. In practice, the observational role which I adopted worked well, although I found myself having to repeatedly remind residents, staff and visitors to the home of my role and the purpose of the research in order to maintain their informed consent. Certainly, there were some residents who were unable to provide their consent to my presence and I had to rely on the views of relatives and/or staff that they would not object. My justification for this is that the role I adopted was not threatening to them and they may even have benefited from my presence in that I was able to provide care which was additional to the normal staffing establishment. On a few occasions, members of staff asked me to undertake tasks which I felt went beyond my own level of competence, for example drug administration, and this could have posed a threat to residents had I agreed.

A further ethical challenge in observational research lies in decisions about what action to take if practice is observed which is detrimental to service users, or even represents a threat to their safety. Within the current research, I observed a number of incidents where the actions of individual staff members posed a serious threat to residents' autonomy, for example; insisting that they had a bath in spite of vigorous protests, refusing to take a confused resident to the toilet on their request, ignoring residents' expressed wishes about where they wanted to sit in the dining room or lounge. I also observed numerous threats to residents' dignity and privacy, particularly through not knocking and waiting for a reply when entering a residents' room, or an occupied toilet, or failing to close a bedroom or toilet door when a resident was in a state of undress. Where possible, I attempted to supplement the care provided, for example taking the resident to the toilet myself. On occasion, it seemed appropriate to challenge a staff member's decision by providing additional information or inquiring as to the rationale for their decision. However, this required a sensitive balance between attempting to meet the needs of residents and not antagonising the staff and I felt I was not always successful. As mentioned in Chapter 3, Madjar and Higgins (1996) suggest that the ethic of care within a research context:

'requires the researcher to take on the responsibility of a moral agent, adapting approaches and actions in response to the needs of the other person(s) in the research relationship rather than adhering to a prescribed protocol'

(Madjar and Higgins 1996 p134)

As previously suggested, this requires skill and flexibility on the part of the researcher and it is unlikely that the most appropriate balance between protecting the interests of individual participants and capturing data with the potential to change practice on a wider scale will always be achieved. The personal demands of collecting data in an environment where the rights of individual older people are regularly ignored have also been vividly described elsewhere (Vesperi and Henderson, Higgins 1998). My own experiences ranged from deep concern that such practices were allowed to continue in some homes to admiration for the highly skilled and sensitive care practices observed in others. The moral standpoint I have chosen is one which aims to describe and understand these practices in order to provide a catalyst for change. This requires a more detailed consideration of the authenticity and trustworthiness of the research in order to demonstrate the relevance of the findings for other individuals and other settings.

Establishing authenticity and trustworthiness

The constructivist approach which informed the research requires that the extent to which the criteria of authenticity and trustworthiness are met is demonstrated. Rodwell (1998) suggests that, given the relationship between the quality of a research product and the quality of a research process, demonstration of elements of trustworthiness will also serve the purposes of authenticity. However, she goes on to say that all dimensions of authenticity cannot be demonstrated through trustworthiness. I will therefore describe the main dimensions of both trustworthiness and authenticity as described by Guba and Lincoln (1989) and by Rodwell (1998) separately, and consider the extent to which I feel each criterion was achieved within the context of the current research.

The main elements of trustworthiness are credibility, dependability, transferability and confirmability (Rodwell (1998) after Lincoln and Guba (1985)). Credibility is concerned with the accuracy of the results and interpretations as viewed by important stakeholders within the context (Rodwell 1998). It is enhanced by prolonged engagement within the research setting (Lincoln and Guba 1985) and requires the researcher to become familiar with the culture being studied. This was facilitated in part in the present study by undertaking the two components of the study in parallel, and learning about the culture of nursing home care while constructing accounts with individual relatives. While I did not observe in all the nursing homes with which my interview participants were involved, I developed insights into the general routines and practices within a range of homes. Although the interview data were based mainly upon exchanges within a single (albeit detailed) interview, I had several contacts with most participants, from the initial contact to engage them in the study, to sending a summary of their account and finally, a summary of the findings of the interviews. About half of all participants returned comments, wrote letters or telephoned following these contacts, enhancing the depth of engagement.

The time spent at each case study site was limited and this represents an important threat to the credibility of the case study observations. However, I felt that I was able to develop relaxed and informal relationships with most participants at all three sites which should have increased the credibility of their accounts and actions while I was present. Wherever possible, insights based on my observations were 'checked out' in discussion with participants, although it was not always possible to reach a shared understanding. Extended, continuous periods of time at the case study sites would have enhanced the credibility of the findings.

Lincoln and Guba (1985) suggest that the member-check, whereby data, analytic categories, interpretations and conclusions are tested with stake-holding groups from whom the data were originally collected, is the most crucial technique for establishing credibility (p 314). Member checks were conducted throughout all phases of the study; during interviews by rephrasing and reflecting my interpretations back to participants, during periods of observation by inviting

participants to comment on my interpretation of events and through written summaries which were shared with participants.

Just under half the relatives who participated in Phase I of the study replied to the initial summary of their interview, mostly to confirm that they were happy with my account. A small number provided additional information and this was added to the data. Three participants felt uncomfortable with the negative views they had expressed and suggested with hindsight that they could have been more positive. However, they stressed that this was not due to my interpretation, rather it was a result of the way they had been feeling on the day of the interview. Only two participants sent comments on the summary of findings posted towards the end of the study. In both cases, their comments suggested that the summary had caused the participant to reflect upon their own situation:

'I wonder whether I could have done more for her.'

'It makes me realise how fortunate we were to find such a good home.'

Neither participant wished to contradict any of the findings presented within the summary. However, a response from only two of thirty-seven original participants cannot be seen as a resounding endorsement of the findings and the potential reasons for this needs to be considered. At the time of posting out the summary of findings I did not feel it would be appropriate to expect each participant to respond in detail given the passage of time since their interview. While the covering letter made it clear that I would welcome comments, and I included a reply sheet and return envelope for this purpose, I did not specifically request a response. With hindsight it may have been more appropriate to negotiate an expectation of continuing involvement and feedback at the outset of the study. The package posted to each participant included a two page summary of key points from the interviews (Appendix XII), an early draft of chapter four of this thesis and a draft of the final chapter including developmental implications of the study. It may be that the language used in these documents was inaccessible to some participants

and they did not feel able to reply. As a result of the limited response to the interview summary from participants, I shared the summary with five personal contacts known to have experience of helping a relative to move into a nursing home. All agreed that the summary encompassed their own experiences suggesting that the findings have currency and resonance with individuals who have experienced this transition.

Responses to the case study reports are described in the section relating to authenticity criteria.

The dependability of research findings within naturalistic research relates to the extent to which the researcher *'seeks means for taking into account both factors of instability and factors of phenomenal or design-induced change'* (Lincoln and Guba 1985 p299) and is demonstrated through the researcher's ability to account for such changes. Examining events from a range of perspectives is one approach to ensuring the dependability of research findings. Rodwell (1998) contends that dependability can be asserted: *'if all perspectives were allowed to have voice and if the data analysis and report represent the multiplicity of perspectives, regardless of assigned or inferred power'* (p 110). While I am confident that the findings of the interview data forming Phase I of the study represent the 'multiplicity of perspectives', this cannot be claimed for the case study data as it was not possible to feed back the case reports to all participants (see below).

Dependability also relates to the appropriateness of decision-making throughout the research and the extent to which this can be demonstrated. Maintenance of a research diary throughout the period of the study enabled me to record key insights and decisions. Tape-recordings of discussions with my supervisor also allowed me to review the basis of methodological and analytical decisions at points within the research process. Finally, use of the memo function within the QSR*NUDIST programme created a record of coding decisions about each element of data. Collectively, these data provide a methodological audit trail, illuminating the process of decision-making throughout the period of the study.

Confirmability demonstrates that the findings of a study are grounded in the data. Achieving confirmability was facilitated by the approach to data analysis, which built up a coding frame from the interview data rather than relying on pre-determined categories. This was helped by the use of open coding within the QSR*NUDIST programme. Confirmability is also demonstrated through the use of multiple quotes from the interview data to illustrate categories, confirming that findings are related to participants and are not just a reflection of the researcher's viewpoint (Rodwell 1998), and through participants' responses to summaries of the findings.

Transferability should not be claimed for any constructivist study (Rodwell 1998). Rather the detailed descriptions of research settings and events provided by the researcher should enable the reader to determine the relevance of findings to their own situation. Detailed information about the circumstances of each of the interview participants presented in Appendix XI enables the reader to identify the range of family situations within which the experiences described are located. The individual case reports based on data collected at each of the case study sites are also rich in description and should enable comparison between homes.

Authenticity criteria The authenticity criteria described in Lincoln and Guba's more recent texts (Guba and Lincoln 1989, Lincoln and Guba 2000), and by Rodwell (1998) include fairness, ontological authenticity, educational authenticity, catalytic authenticity and tactical authenticity. These criteria are described in some detail In Chapter 3 (page 60) of this thesis. In brief, fairness is the extent to which all voices are represented in the research; ontological authenticity requires increased awareness of the complexity of the issues under investigation on the part of those being studied, educational authenticity requires that they gain an increased understanding of the values and viewpoints of others, catalytic authenticity that the research provides a stimulus for change and tactical authenticity is concerned with the degree to which the research empowers, or potentially empowers, change. These criteria will be considered separately in relation to the two phases of the research.

Fairness involves the even representation of all viewpoints (Rodwell 1998). Within the current study, an attempt was made to ensure that the voices of all stakeholders with an interest in relatives' experiences of nursing home entry were heard. This included the relatives themselves (Phase I and Phase II), other family members (Phase I and Phase II), residents (Phase II) and staff (Phase II). Rodwell insists that 'fairness' does not just involve ensuring that all accounts are included in the analysis but that all participants have the opportunity to participate in the analysis and interpretative stages of the inquiry. Again, feeding back a summary of each interview, and then a summary of all interviews and inviting comments and feedback at each stage was an attempt to ensure that all participants in Phase I of the study had the opportunity to contribute to the analysis and interpretation phases of the research. However, less than half the participants responded to either contact. This is likely to be due in part to the time-scale for the study: the summary of interview findings was not available until some three years after the first interview. I therefore felt it would be inappropriate to send the summary directly through the post and initially sent a brief letter, indicating that the summary was now available but acknowledging the length of time since the interview and that the participant's situation may have changed. I invited them to return a reply slip indicating if they would like to receive the summary. Twenty-five of the original 37 participants responded to this contact and it is likely that at least some of the participants had changed address in the intervening period. An alternative explanation is that their own situation may have changed and they may have decided that they were no longer interested in participating in the study.

The extent to which I am able to demonstrate ontological, educational, catalytic and tactical authenticity in relation to the findings of the interviews is limited. It is possible that simply by discussing their experiences, participants may have increased their awareness of the various factors which have shaped and created these experiences. Certainly many participants expressed appreciation for the opportunity to talk with me and said they felt they had benefited. Similarly, by sharing my own views of current practice within care homes and on the constraints under which care staff are operating, it is possible that participants' awareness and

understanding of the values of others may have been enhanced. However, I have no firm evidence of this.

Attempts to engage all participants at the case study sites in the processes of analysis and interpretation met with variable success. The case reports were shared, initially with the manager and senior nurses at each site. The response was variable and affected the extent to which it was possible to establish that the remaining authenticity criteria had been achieved. Each case study site will therefore be considered separately in relation to these criteria.

At the first case study site, a modified version of the case study report was given to the nurse manager who circulated a copy to all qualified staff (Appendix XIII). A meeting was then arranged to discuss the report, and was attended by the nurse manager and five qualified members of staff. Those present said they were shocked by the report but accepted that it was accurate. During a tense meeting, they conceded that they felt so pressurised and short of staff that they were essentially 'firefighting' and had little time to think about developing practice to involve relatives further. I offered to run a short series of educational sessions to which all staff could be invited, picking up on key findings of the report and identifying possible ways forward. This was readily accepted and I prepared a short programme of six sessions which could be repeated to ensure that all staff had access. I suggested that I would run the sessions initially but that I would leave the resources for a qualified member of staff to deliver the sessions subsequently.

The first session was attended by seven staff members, including six care assistants and one staff nurse, and the findings of the case report were shared. However, those present contributed little to discussion and it was difficult to ascertain the extent to which they were in agreement with my findings. Subsequent sessions were designed to focus on improving relatives' experiences and quality of life for residents. Two sessions were designed to focus on clinical issues at the request of staff. Unfortunately, these sessions had to be repeatedly rearranged due to staff shortages, and when they did take place were attended by

between two and four members of staff. I left the resource packs as agreed but have no evidence as to whether the sessions were repeated. Due to the time constraints of the study, it was not possible to return to the home to assess whether practice had changed as a result of the study and feedback. Two years after the period of observation, I learned that the home had closed.

At the second case study site, the case report was posted to the general manager some four months after the final observation. A meeting was arranged to discuss the report, but this was attended only by the general manager, the nurse manager and myself. It transpired that both had been extremely unhappy with the contents of the report and disputed many of my findings. My field notes from this meeting are included as Appendix XIV.

Through discussion, I became aware that my interpretation of events and relationships at this home had neglected some important factors and I felt able to modify my interpretation accordingly. However, in other respects, I was not persuaded from my initial interpretation by the additional information provided during the meeting. Although I produced a modified report following this meeting, these managers were not happy for the report to be circulated more widely. It was therefore impossible to establish the extent to which the authenticity criteria were met for this site.

At the final case study site, the case report was initially shared with the nurse manager and deputy nurse manager. They were delighted with the report and agreed that it accurately represented practices and relationships within the home. We discussed the most appropriate way to negotiate the findings with other staff members and with relatives and residents and agreed that this could happen in a variety of ways: through informal conversations with staff, residents and relatives, through a brief presentation at the relatives' meeting and through a teaching session with care assistants. Through each of the methods, it was possible to establish that participants shared the views and observations presented within the case report. I was able to contribute insights which had emerged from the study as a whole at a relatives' meeting and perceived that this had an effect on the way

that subsequent meetings were organised. However, beyond this, it was again impossible to demonstrate that the remaining authenticity criteria had been achieved within the time constraints of the study.

Rodwell asserts that the notion of authenticity criteria is still under development and encourages researchers to experiment with different strategies to ensure and demonstrate authenticity and to make the empowerment dimension of research rigour real and realisable (Rodwell 1998). My own experience suggests that these strategies need to go beyond simply feeding back and negotiating the findings of a research study in the hope that this will result in enlightenment and action. Furthermore, the use of strategies intended to empower research participants can have the opposite effect. The potential for participants to be faced with observations which may be unpalatable and even emotionally damaging presents a real ethical dilemma for the conscientious researcher, but has not been considered extensively in the literature on constructivist inquiry. My experience suggests that there may also be a significant threat to research participants unless the purpose and nature of these strategies are clearly negotiated at the outset.

Further challenges are likely to result when it proves impossible to reach a shared interpretation, and the researcher is left with the dilemma of whether to present their own interpretation or that of the research participants. In this case, I chose to present the modified case report, but there is no doubt that my initial observations have shaped the synthesis of findings presented within this thesis. It has not been possible to share the synthesis of the case study data with research participants, in part because of the time scale since the observations were undertaken. One of the case study homes has closed and at all three sites, residents have died, relatives have ceased to be involved and senior personnel have moved on. Demonstrating that ontological, educational, catalytic and tactical authenticity have been achieved is likely to require particular strategies which enable participants to provide focused feedback on what they feel they have gained from their involvement in the study. This aspect needs to be planned at the outset of the research and incorporated into budgets and time-scales.

In spite of these limitations, there are indications that the findings of this research resonate with a wide audience of family caregivers and practitioners. Presentations of preliminary findings to both lay and professional audiences have prompted many individuals to comment that the findings reflect their own experiences. It is suggested therefore that the findings do have currency and value within the current context of practice and that they provide new forms of insight and understanding. According to Morse (1994) the true strength of qualitative findings is in their 'recontextualisation', that is being held up to current knowledge and correspondingly the study findings are now considered in the light of pre-existing and concurrent literature.

Synthesis of findings with other literature

The original aim of this research was to develop a deeper understanding of the needs of relatives and family caregivers of older people who move into a nursing home, in order that nurses and other health care practitioners may be better prepared to meet those needs. Relatives described to me their experiences of helping a relative to move into a nursing home and continuing to support them within that setting. Contemporaneously, I undertook observational case studies within three nursing homes in an attempt to explain relatives' experiences through an analysis of current practice within nursing homes. In line with other research, the relatives I interviewed described their experiences temporally. Three phases were described: 'making the best of it' which involved decision-making about long-term care options, 'making the move' which was concerned with the practical arrangements for moving into the care home and early efforts to adjust and 'making it better', relating to the ongoing experience of continuing to support an older person within a new care context. Findings from both the interviews and the case studies which relate to each phase will now be synthesised and then compared with findings from the literature. However, first I will present what I feel to be the major findings of the current study.

Key findings of the current study

Without doubt, moving into a residential or nursing home is a major life event with important repercussions for older people and their family members. Findings of the current study suggest that relatives' experiences of helping an older person to move into a care home are extremely variable. However, the extent to which they feel that they are working in partnership, both with the older person, with other family members, and with service providers, to achieve what is best for the older person appears to be fundamental to a good experience. Working in partnership encourages and enables relatives to feel supported, well-informed and in control. They are then in a stronger position to deal with the many pressures which impact upon their lives throughout the period of supporting an older person to move into a care home.

Data from both phases of the research suggest that the behaviour and reactions of health and social care providers are crucial in shaping the experiences of older people and their relatives in relation to the move to a care home. However, findings suggest that practitioners are themselves operating within contexts and boundaries which affect their ability to work in partnership with older people and their families. An appreciation of these contexts is essential to an understanding of how the experiences of older people and their relatives can be improved. Participant observation within the second phase of this study suggested that individual care homes can develop very different cultures of care and that these cultures in turn influence, and are influenced by, the experiences of residents, relatives and staff. The culture within a particular home is influenced by the values held by staff, particularly those in senior positions, and by the model of care in operation. These factors in turn determine perceptions of roles and the nature of relationships within the home. Historical traditions, availability of resources, leadership style and expectations of service users are also likely to play a part. However, crucially it would appear that staff, relatives and to a lesser extent residents also have the potential to influence the culture or 'type of community' which is created.

The original objectives for this research (see Chapter 1 page 11) suggested that the experiences of relatives in relation to nursing home entry would be considered separately from an examination of care practices within nursing homes. What emerged as the research unfolded was the inappropriateness of trying to separate out these two elements. Therefore, the following discussion will use the phases of the experience as described by the research participants as a framework, in order to demonstrate how relatives' experiences are influenced by care practices during each phase. Key findings in relation to each phase will now be summarised and compared with contemporary literature.

Making decisions about long-term care options

The move into a care home is prompted by a range of situations, some involving a sudden crisis demanding immediate action, others involving a gradual deterioration prompting discussion about suitable care alternatives. What is clear from the interviews carried out during Phase I of this study is that relatives' responses to these situations are influenced by a wide range of factors, not least the actions and responses of health and social care practitioners. In other words, the potential for relatives to feel that they have made, or been enabled to reach a decision, rather than being forced to accept the decision, can be realised if they have access to relevant information, feel able to retain control of events as far as possible, are supported to discuss their opinions and feelings and are not subject to undue pressure. For the majority of participants within this study, this was not their experience.

For most relatives, their wish to make a good choice with, or more commonly for, the older person needs to be balanced with a host of other factors, including the views of other family members, the views of professionals and their own ability to continue to care. All of these factors result in pressure to make decisions quickly. Furthermore, achieving what they feel is best for the older person is often constrained by factors outside of their personal control. Within the current study, the views of service providers and the lack of availability of suitable alternatives to nursing or residential home care were particularly important influences on decision-making.

The most positive experiences of this initial phase appeared to result when the decision to move into a care home and the choice of home were able to take place without pressure of time or resources. Where recognition of need resulted in ongoing discussion between family members over a period of time, decisions could be made without duress. However, the interviews carried out during Phase I of the study provide little evidence that the possibility of admission to a care home had been anticipated, either by the older person or their relatives. On the contrary, several participants described how they had previously promised their relative that they would never have to move into a nursing home, resulting in overwhelming feelings of guilt when the decision was finally reached. This suggests a potential role for community-based practitioners and hospital staff in encouraging older people and family members to explore long-term care options at an early stage. Ideologically, this may appear to conflict with current community care policy and the prevailing view of the 'institution'. Consequently, there is a concurrent need to reconceptualise to some extent, the role of institutions in long-term care, a point which will be returned to later.

Similarly, few older people were perceived to have been fully involved in the selection of a home. In some cases it had even been impossible for the older person to visit the home prior to moving in, usually due to difficulties in arranging transport or pressure to vacate a hospital bed. In more than half the cases described, the relative had made the final decision about the home, most commonly as a result of the cognitive frailty of the older person. Consequently there was often little opportunity for the relative to work together with the older person to achieve the best outcomes. Support services during this period were often fragmented, limiting opportunities to build up a relationship with service providers. Where relatives did receive ongoing support during this period, from a named individual who they felt appreciated their own needs, then this was perceived as enormously helpful. However, this was the exception.

The absence of ongoing support from a named individual may explain the perceived lack of information to help older people and their relatives to make decisions about admission to permanent care, which is a recurring theme within

my interview data. Relatives particularly felt that they needed information and advice about alternatives to long-term care, about financial issues, and on what they and their relative could expect in terms of levels of care and activities within a home. They also craved comparable information to help them decide between homes. On the whole, those who had received adequate support and information to help them plan the move perceived the transition much more positively.

Relatives frequently described how they had engaged in information-seeking behaviour, but faced numerous barriers. However, few attempts were described to access 'role models' in the form of family caregivers who had experienced a similar transition and made a successful adjustment. Very little reference was made to service user groups, although where these had been accessed they were found to be universally helpful. Furthermore, professional care staff seemed to have made little effort to encourage such exploration. Very few relatives perceived that they had had the opportunity to discuss their feelings and explore alternatives to admission with health and social care personnel. In summary, few of the requirements that would enable older people and their relatives to perceive admission to permanent nursing home care as a positive choice were present in the experiences of those interviewed.

Importantly the study identified a number of factors that help to explain why so few carers experienced a 'positive choice'. These were described in detail in chapter 4 and include feeling under pressure, feeling that they were 'working in the dark' without adequate information, feeling out of control and a perception that they were working almost in opposition to health and social care staff. These findings resonate closely with those of Kellett (1999), who, on the basis of longitudinal interviews with fourteen family caregivers in Australia, describes five shared categories of meaning in relation to the relocation decision. These are: experiencing a loss of control, being disempowered, feeling guilt, sadness and relief simultaneously, possessing a sense of failure and having to make a forced and negative choice. Although some of these experiences may be inevitable consequences of the context in which the move is made, awareness of them does

have implications for interventions which might ameliorate the situation. These are considered in the next chapter.

Meanwhile, it is apparent from both the findings of the current study and the literature that the decision for an older person to move into a nursing home is a complex process involving multiple stakeholders, multiple decisions, distinct phases, variable modes of interaction between the actors, and variable outcomes that are provisional and may change over time (Groger 1994, Bell 1996, Keefe and Fancey 2000). The notion that relatives experience many pressures around the time of admission to a nursing home finds support within the literature, with the process commonly described as hectic and stressful and occurring mostly within the acute crisis of hospitalisation of the older person (McAuley *et al.* 1997, Morgan *et al.* 1997). In particular, the dominance of medical opinion in determining outcomes mirrors the findings of the initial literature review (Cosbey 1994, Chenier 1997, Wright 1998). More recently, in a qualitative interview study with ten family caregivers, Ryan and Scullion (2000a) also found that the views of health care professionals and of other family members were important factors. These authors found that some carers appeared to distance themselves from the admission and postulated that this may be an attempt to legitimate the decision. However, Kadushin and Kulys (1994) suggest that where decision-making about long-term care involves health and social care professionals, it becomes a social process involving negotiation and power. As a consequence, older people and their family caregivers may feel they do not have the power to influence the implementation of their own wishes.

The findings of the current study resonate with the attributes of successful transitions described by Nolan *et al.* (1996b): anticipation, participation, information and exploration, (see Chapter 2 page 27). In particular, the importance of adequate information to support decision-making has been highlighted recurrently within recent literature (Bell 1996, Dellasega and Nolan 1997, Wright 1998, Pearson *et al.* 1998, Ryan and Scullion 2000a). In relation to preparation for the move the literature provides some guidance for practice (Armer 1993, Reed and Payton 1995, Morgan *et al.* 1997). On the basis of semi-structured

interviews with 50 older people living in residential settings in New York, Armer (1993) for example suggests that predictability can be enhanced through exploration of expectations, tours of the new environment and examination of cultural and geographical familiarity with the new environment. It is notable that these aspects of preparation were not commonly experienced by participants within this study. Oldman *et al.* (1998) recommend that providers must recognise the role of relatives in residential care and should make their policies explicit from the outset. Ross *et al.* (1997) describing wives' experiences of their husband's admission goes as far as to suggest that initially, wives should be viewed as clients and familiarised with the organisation of the home and who will be involved in their husband's care. This leads into a consideration of experiences of relatives in relation to the period around the move itself.

Making the move

The period around the move into the nursing home was particularly traumatic for many relatives, involving a process of sudden adjustment to being without the older person on a day to day basis, as well as the need to undertake many practical tasks. However once again, the actions of health and social care practitioners had the potential to make a difference to experiences at this time. For example, the financial aspects of moving into a care home are often complex, difficult to understand and organise, and can put severe strain on a family's finances. Such experiences were commonplace for participants within the current study. However, an important finding was the potential for knowledgeable health and social care practitioners to help guide carers through the maze and enhance their understanding of the system. This kind of support, coupled with an approach that allowed the older person and their relatives to take time to plan the move, could make all the difference between experiencing the move as 'a nightmare' and 'a smooth ride'. This finding has important implications for all practitioners involved at any stage of the move to a care home.

The day of the move into the home can be a particularly difficult time and practical arrangements, such as appropriate transport, a warm welcome on arrival and ensuring that the older person's room is prepared can make a traumatic

experience easier to deal with. For some relatives within the current study, memories of the day of admission remained vivid, even when this occurred several years previously. This was especially the case where the experience had been particularly traumatic.

The current research found little evidence that prospective residents and their relatives had been prepared in relation to what to expect in terms of the day-to-day routine within a home and the roles occupied by different members of staff. Furthermore there appeared to be few attempts to discuss with relatives how they perceived their future role within the home. Aspects such as charges for 'supplementary' services for example also came as a surprise to many. Few relatives had made more than one visit to the home prior to the older person's admission, and apart from the few cases where the older person had moved into the home which had provided respite care, none had had the opportunity to stay overnight prior to moving in.

Findings from the current study suggest that relatives see themselves as having a responsibility to make the older person 'familiar' to staff and residents, in addition to creating familiarity for themselves. However, it appears that the assessment of an older person's needs on admission to the home frequently fails to draw upon relatives' expertise and knowledge. Furthermore, although care home staff were generally supportive, few relatives felt that their own needs were assessed at this time. The small number of admissions observed during the case study investigations suggested that the admission process often takes place in a rush, with little opportunity for anticipation and engagement in advance. The extent to which care staff seemed familiar with residents' family background and the needs of relatives varied between homes and may be a function of the size of the home: in smaller homes with fewer residents there are fewer relationships to build. Certainly, the most positive experiences of feeling that their needs were seen as important by staff were described by relatives at the smallest home observed. This was also the case for relatives interviewed in Phase I of the study.

Both the current study and the literature suggest that the period around moving into a home is one of adjustment, both for the new resident and their family carers. Relatives commonly struggle to adjust to changes in their relationship with the older person, changes in their role and changes in the pattern of their day.

Within the current study, few differences were observed between the experiences of spouse and adult child carers. A more important distinction appeared to be whether the older person was co-resident prior to the move. Most spouses described the devastating impact of no longer living with their life partner. However, adult child caregivers, particularly those who had remained single, also described the loss of their 'best friend' and the negative impact of living alone. This finding suggests the importance of avoiding assumptions about the impact of the move, based upon the relationship of a relative to the older person. Observations at the case study sites revealed how the environment of care could increase staff members' awareness of whether a relative was experiencing difficulty in adjusting to the move and enable relatives to access support. Where relatives had the opportunity to engage regularly with staff members in communal areas, this appeared to enhance their experience of support at this stage.

Differences in patterns of behaviour following the move described by participants in the current study relate largely to visiting the older person. Opportunities to engage in simply 'being with' the older person, rather than needing to perform physical and domestic helping activities were welcomed by many. However, visiting in a 'public' environment could also result in a certain amount of strain, particularly when the older person was cognitively impaired and difficult to engage in conversation. Again the importance of having staff members around to make family members feel welcome and at ease, and to join in the conversation where appropriate was apparent from the observations at the case study sites.

The threat to family caregivers' sense of personal identity prompted by the move to a nursing home has been described in several recent studies (Tilse 1997, Fleming 1998, Ryan and Scullion 2000b). Changes in the sense of personal identity are commonly linked with changes in roles and relationships. Within the

current study, several relatives mentioned their reluctance to relinquish the main caregiving role, to 'let go', although specific references to a sense of identity were rare. Participants were able to describe ways in which they perceived their relationship with the older person to have changed since the move. However, it was difficult to differentiate between the effects of the move to a nursing home and the consequences of on-going deterioration in the physical and mental health of the cared-for person.

There is some evidence within the literature of the effects of nursing home admission on family relationships. Smith and Bengtson for example (1979), reporting findings of interviews with 100 residents and close family members in one Scandinavian long-term care facility, found five types of consequence: renewed closeness and strengthening of family ties (found in 30% of cases), discovery of new love and affection (15%), continuation of closeness (25%), continuation of separateness (20%) and quantity without quality interaction (10%). Abdication, a sixth consequence hypothesised by the researchers was not apparent within the data. While many relatives within the current study remained very close emotionally to the older person, discovery of new love and affection was not described as a consequence of the move. However, the remaining categories identified by Smith and Bengtson are consistent with the current findings. Not surprisingly, there are suggestions within the literature that, if the older person is unhappy following the move, this can have a negative impact on family relationships (Bell 1986) and again there were examples of this within my data.

Based on the literature it has been difficult to form conclusions regarding the differential effects of relocation of an older person to a care home on caregivers depending on their relationship to the family member who has relocated (King *et al.* 1991). Friedemann *et al.* (1999) found that adult daughters were more likely to be involved in direct caregiving tasks following the move than other relatives. King *et al.* (1991) found that the decrease in perceived impact on daily schedule was significantly less for spouses than for adult children, possibly reflecting the greater amount of time that spouse caregivers reported spending with the care recipient following institutionalisation. Spouse and other caregivers reported an

increase in stress related to health and finances while adult child caregivers reported a decrease in these areas.

Rosenthal and Dawson (1991) conceptualise the process experienced by wives whose husbands have entered a long-term care home as a life course transition which they term 'quasi-widowhood' comprising four stages. It is worth describing these stages here in some detail as they resonate clearly with the experiences of spouse caregivers described within this study. Stage 1 for example was characterised by feelings of ambivalence, uncertainty about the future, and a predominance of intrapersonal concerns such as loneliness and depression. Stage 2 on the other hand was characterised by a shift to an interpersonal focus. The wife's improved physical and mental health enable her to focus more on interpersonal concerns such as the relationship with her husband. This may result in increased visiting, greater input into care tasks and some conflict with staff. Stage 3 is characterised by the relinquishing of some roles and the adding of others as wives negotiate altered definitions of responsibility, appropriate behaviour and task performance, including a broadening of social activities within the home. Confidence and trust in the staff are likely to increase along with role clarity leading to a reduction in conflict. The final stage in the process is characterised by resolution and adaptation. The wife achieves a balance of her own needs with the patient's needs, feels comfortable in the institution and accepts the changed spousal relationship and the likelihood of decline in the patient's condition. Rosenthal and Dawson (1991) suggest that typically it takes spouses eighteen months to reach stage 4. However, they take pains to emphasise that the stages they describe are fluid and the result of social action rather than an unfolding of inevitable 'inner processes'. Once again these findings highlight the potential for health and social care practitioners to make a difference in enabling relatives to adapt to the new environment. This potential was clearly apparent from my interviews with spouses, and observation of spouses visiting within the case study nursing homes. Where spouses were made to feel welcome and to consider the care home as a second home, where they were encouraged to continue to provide physical care for their spouse if they wished to and where they were afforded

regular opportunities to discuss any concerns with care home staff, spouses appeared to adjust to the new arrangements more easily.

Older people and their relatives will adapt to life in a nursing home in a variety of ways and support needs to be tailored accordingly (Savishinsky 1991, Patterson 1995, Reed and Payton 1996). Reed and Payton (1996) argue that care staff need to recognise the hard work that older people perform when they move into a care home in relation to fitting in with existing conventions and rules, what they term 'constructing familiarity and managing the self'. The findings of the current study suggest that family caregivers may have to undertake similar activities in order to 'fit in' with the culture of the care home and to 'make it familiar' (see chapter 4 page 120).

Some relatives and some staff members within the case study nursing homes identified a need for information and preparation for relatives in order to assist them to adjust to their new role. At all three case study sites, staff members identified relatives' expectations of care as a potential inhibitor to person-centred care in some cases. Examples included requesting that a resident's mobility should be restricted in order to reduce the risk of falls and in demanding that a resident should be bathed regularly even where this conflicted with the resident's expressed wishes. Although many family caregivers possess 'expert' knowledge in caring for their relative within a familiar context, their knowledge may be insufficient to meet the demands of the new situation. A number of studies (McDerment *et al.* 1997, Wright 1998, Rantz *et al.* 1999) have demonstrated a need for educational interventions aimed at:

- ◆ involving relatives in providing stimulating activities for residents;
- ◆ preparing relatives for what to expect in relation to a resident's condition;
- ◆ encouraging relatives to participate in nursing home life;

- ◆ communicating with residents in ways which enhance life satisfaction and quality of life.

To encourage continued family involvement, care staff need to recognise, and respond to, the family's need for information about the changing needs of the resident, in a process of continuing dialogue and negotiation. There is certainly evidence, both from the current study and within the literature that relatives want more information about the condition, illnesses and limitations of the older person (McDerment *et al.* 1997, Rantz *et al.* 1999). From the staffs' point of view other commentators have highlighted the need to attempt to influence relatives' attitudes, for example in relation to risk management (Molasiotis 1995) and the need for services (Warren *et al.* 1992). Staff, residents and their families all require preparation in order to understand the demands of the system and the roles and behaviour required to ensure effective service provision (Shulman and Mandel 1988). Relatives may also need information and guidance from staff in relation to decisions which they make on behalf of nursing home residents (High and Rowles 1995), for example in relation to dental treatment (Warren 1992). Ryan and Scullion (2000b) found that family members regarded care plans as a nursing issue, suggesting low levels of engagement in the process. These findings also highlight the potential for educating relatives about the potential value of their involvement in care planning.

Developing a caring role within the context of the care home

The findings of the current study confirm that relatives attach a great deal of importance to their continued involvement in the life of the resident following the move. In interviews, relatives described their role in ensuring best care as having three main components:

- ◆ ***Maintaining continuity:*** helping the older person to maintain their sense of identity through the continuation of loving family relationships and through helping the staff to get to know them as an individual;

- ◆ *Contributing to a sense of community* within the care home, by interacting with other residents, relatives and staff, taking part in social events and generally providing a link with the outside world;
- ◆ *Keeping an eye*, by monitoring the care received, providing feedback to staff and filling any gaps.

For most participants within the current study, their caregiving role following placement contrasted with that prior to admission to the home, which had revolved more around practical and supervisory caring activities. However in interviews with 214 relatives, Keefe and Fancey (2000) found that 53% of their participants did not perceive any changes in their responsibilities towards their relative following the move. These participants described two main types of involvement: direct and indirect. Indirect involvement included acting as an advocate and overseeing activities within the home. Relatives described an on call role and highlighted the importance of establishing and maintaining a relationship with staff. Direct involvement includes providing emotional and physical support, providing personal comforts and being a link to the community. These links were felt to be particularly crucial:

'Residents in long-term care facilities were often vibrant members of their families and communities. To assume that they are no longer interested in the outside world is to deny them the right of citizenship. Family members who continue to engage and inform the resident of current events contribute to fostering the resident's identity and purpose'

(Keefe and Fancey 2000 p 240)

These findings mirror the desire to maintain continuity identified within the current study. On the basis of participant observation in four nursing homes, Rowles and High (1996) describe a number of caregiving roles for relatives following admission. Some of these roles, such as comforting and pampering, mirror activities prior to admission. However, other roles including engaging or re-engaging in familiar aspects of their life, educating staff, monitoring care and

mediating between staff and resident, represent a distinct role shift. Again there are parallels with the findings of the current study.

In relation to developing a new role within the care home setting, Kellet (1998) identifies eight shared meanings which she suggests illuminate the various ways in which family caregivers strive to create possibilities to care, enabling them to attribute meaning to their everyday involvement in caring for their relative. These shared meanings are presented in Table 6.1, together with suggestions of how they reflect the roles described within the current study. Kellet argues that it is vital that nurses learn from those who find meaning in continuing to care following admission to a care home, in order to assist those who are struggling to perceive meaning in their new role. There are implications here for supporting and guiding relatives to engage in activities which might help them to recognise possibilities to make a difference in the life of the older person.

Table 6.1 Categories of meaning for relatives of older people living in care homes

Eight shared meanings	<i>Maintaining continuity</i>	<i>Contributing to community</i>	<i>Ensuring best care</i>
Feeling duty bound	X	X	X
Setting up possibilities for human connection	X	X	X
Possessing special knowledge and skills	X	X	X
Providing the personal approach	X	X	X
Acting as an advocate		X	X
Living with hope of improvement and recovery			
Feeling satisfied when care experienced was deemed to be quality care			X
Possessing a sense of worth through making a useful and positive contribution	X	X	X

X – study findings support the notion that this factor contributes to ‘meaning’ during this phase

(Adapted from Kellet 1998 p14)

In a similar vein, Fleming (1998) describes how family caregivers provide a lifeline of special care for their relative following placement. On the basis of qualitative interviews with 14 family caregivers, primarily adult daughters, Fleming postulates that it is through the lifeline of special care role, family caregivers give themselves self-respect and a purpose to their lives:

'The lifeline of special care roles gives dual meaning to caregiving activities. On the one hand the caregiving activities are directed towards the care-receiver maintaining the quality of life of the care receiver. These purposes include care to protect or preserve the care-receivers self and to prevent physical harm to the care-receiver. At the same time, the caregiving activities become part of the construction of self process for the caregiver. This dual meaning can be expressed as 'I am doing it for her and I am doing it for me.'

(Fleming 1998 p142)

Fleming suggests that the meaning of the 'lifeline of special care' activities is crucial to the understanding of the reasons why caregivers continue their caregiving 'careers'. In other words the lifeline of special care is sustaining for both caregiver and care-receiver alike.

Roles following the move described by family carers within the current study resonate clearly with the six categories of family caregiving described by Bowers (1988): anticipatory, supervisory, preventive, instrumental, protective and preservative care. In particular, relatives' attempts to create continuity and to ensure best care reflect these elements. The findings of both Kellet (1998) and Fleming (1998) also resonate clearly with many of the observations and experiences of my research participants. More specifically, the motivation of many of the family caregivers I interviewed to make a difference in the life of their relative articulates with Fleming's notion of a lifeline of special care. The reciprocal benefits for family caregivers in terms of maintaining their own identity and sense of self are also apparent in their descriptions of the satisfaction of knowing they are making a difference for their relative. What is perhaps missing from accounts within the literature, but was an important finding within my case study research, and to a lesser extent the interview data, was the potential for

relatives to make an important contribution to the sense of 'community' within the home, not only for their own relative but also for other residents and staff members, and to exert an influence on the dominant culture within the home. The various factors which contribute to this culture will now be summarised.

Creating cultures of care which value relationships

Data from both phases of the current study suggested that the extent to which relatives were able to achieve their aim of ensuring best care for the older person was dependent in large measure upon the culture of care operating within the home and the actions and responses of care staff. Most relatives within the study had a clear understanding of the standard of care they wanted for the older person but for some relatives, the reality of care frequently failed to meet these expectations. In particular, where staff were unwilling or unable to develop close working relationships with relatives then care was frequently perceived as lacking. In these circumstances relatives used a range of strategies to try to improve things, including showing staff how to deliver care, making requests and making formal complaints. However, a significant proportion of relatives appeared to feel that they had no option but to 'keep quiet' in order to avoid upsetting staff and possibly further jeopardising their relative's care.

Within the current study, the way in which care home staff responded to relatives' attempts to achieve the best possible care resulted in one of four possible types of relationship with staff. These were:

- ◆ Partnership care - 'Working together';
- ◆ Substitutive care - 'Doing it yourself';
- ◆ Submissive care - 'Putting up with it';
- ◆ Conflict in care - 'Battling it out'.

The final three types of relationship left relatives feeling frustrated and angry or resigned to their situation. Where partnership care was achieved, this had positive benefits for relatives, for residents and for staff. The final stage in family caregiving could then be experienced as a time of enrichment for all involved. The key question this leaves is how can partnerships be forged in the most realistic way?

Characteristics of the nursing home environment which support effective partnerships between staff and relatives include flexibility, effective communication and perception of shared goals. Flexibility for example involves a recognition that everyone has individual needs and that individuals adapt in different ways. The significance of effective communication between staff and relatives was a recurrent theme within the current study. Participants described how, when support was lacking, or communication with professional staff was less than optimal, they experienced feelings of powerlessness, confusion, frustration and conflict. Conversely, staff making time to talk and keeping family carers informed about their relative's condition emerged as key elements of 'best care' as perceived by family members. The importance to relatives of perceiving that staff share similar goals for the older person resident in a care home also figured prominently in their descriptions of best care.

The case studies suggested that staff responses to residents and relatives within a care home and the relationships which develop as a result are shaped by a number of factors. These include the implicit values of the organisation, the way in which care objectives are conceptualised and the way in which work is negotiated and carried out.

The findings of the current study in relation to the final phase of the experience for relatives, that of creating a role within the home in order to 'make it better' for the older person, resonate closely with existing literature but also extend our knowledge in several important respects. In particular, an important finding of the current research is that relatives' experiences of nursing home entry cannot be considered in isolation from the experiences of the older residents and staff of care

homes. In some homes, relatives' experiences of lacking information, of not being in control, of working in isolation, feeling under pressure and lacking support were mirrored by the experiences of individual staff members. Furthermore, findings from case study research within three nursing homes suggest that these experiences are largely a consequence of the dominant model of care in operation within a home.

The importance of a common philosophy and shared goals for relatives and staff finds support within the literature. For example, relatives have highlighted their desire for residents and families to be the agency's top priority rather than making money and profits (Rantz 1999). Rantz compared staff and relative perceptions of what constituted a quality service and found that relatives recounted anxieties about negative experiences such as accidents and loss of belongings, whereas these issues were not highlighted by staff. In a similar study comparing the views of relatives and staff, Ryan and Scullion (2000b) found that while the resident was the focus of care for both family and nursing staff, delivery of that care was guided by different considerations:

'Nursing staff followed and were inhibited by policies and procedures within a professional relationship. In contrast, families derive their caregiving role from existing family structures, values and established relationships. Staff perceptions of care reflected the culture of the institution, whereas family care reflected a more complete human concern'

(Ryan and Scullion 2000b p632)

More than a decade previously, Minichiello (1987) argued that such discrepancies arise from managers attempts to standardise and routinise services, resulting in the creation of unintended rules. Such rules rarely serve the goals of both the institution and the interests of individual clients. Friedemann *et al.* (1999) further highlight the ways in which nursing home rules and policies may influence family involvement:

'When confronted with difficult situations, families have been observed to sustain their pre-established patterns of functioning. Consequently, if not inhibited or influenced by institutional factors, families who admit a member to a nursing home would be expected to expand their family process to include the nursing home and assume roles that are consistent with their usual behaviour patterns. Family related nursing home policies and practices would therefore constitute institutional factors that have the potential to facilitate or inhibit family involvement.'

(Friedemann *et al.* page 551)

Rigid policies and inflexible rules have repercussions for both residents and relatives. Nelson (2000) suggests residents often try to enlist family members to help them to win concessions: however, these family allies are often frustrated because they are, relatively speaking, without resources themselves. The result is often an 'impotent retreat' or 'angry retaliation' with the complaint carried higher and higher in the chain of command. This parallels the experiences of relatives within the current study who were forced either to 'put up with it' or 'battle it out'. Nelson, after Litwak (1985) attributes this situation to the bureaucratisation of care and a clash of value systems:

'It is apparent that most nursing home complaints stem from the institution's poor translation of an essentially intimate family caregiving function into the impersonal mechanisms of a bureaucracy (Litwak 1985). The impersonal and incomplete care that results creates frustration surrounding issues of autonomy, better service, and individualised care - the core rewards in the consumer's value system. Conflict arises from clashes between this value system and the facility's value system that embraces efficiency, profit, risk management and proper care as well as other medical, managerial and professional prerogatives. Although these goal sets are not always in conflict, the provider's concern for the individual patient's interest is inherently limited by facility priorities and the need to sustain managerial power and control.'

(Nelson 2000 p48)

Nelson argues that patient (resident) advocates are essential in order to achieve an appropriate balance which meets the needs of the older person, their family and the organisation.

Taken together the findings of the current study and of the existing literature suggest that the potential to create appropriate cultures of care for older people and their relatives is unlikely to be realised unless the needs of all stakeholders, including staff members, are taken into account. A recurring theme within recent literature is the need to acknowledge the emotional component of work with older people and family caregivers if true partnerships are to be created. Gattuso and Bevan (2000) for example suggest that the kinds of phenomena which must be accounted for in a theory of emotional labour include the blurring of 'public' and 'private' in women's experiences and maternal models of care. They argue that the welfare of the recipient of gerontic nursing is linked to the well-being of the nurse carer but that a cultural change is needed so as to recognise and value emotion work. These arguments resonate with Brechin's assertion (Brechin 1998) that any analysis of care must address the experiences of all those involved so as to tease out the tensions and pressures which mitigate against good care in order to help identify and build appropriate support (see Chapter 5 page 211). Other studies have also identified a need to expand the current conceptualisation of caregiving to place a greater emphasis on emotional support (Keefe and Fancey 2000, Oldman *et al.* 1998):

'There is still too much emphasis in quality standards, on the quality of physical care and not enough on the need for good social relationships, having enough to do, going out of the home. These issues are not easily addressed.'

(Oldman *et al.* 1998 p 64)

The difficulties for practitioners of reconciling the realities of practice with traditional care models has also been highlighted (Hasselkus *et al.* 1996). More than a decade ago Safford (1989) recommended practice models to overcome such tensions by co-ordinating and joining the shared functions of formal and informal

support. As a possible way forward, Bond and Fiedler (1998) propose a social model of care with the following goals:

- ◆ to promote a resident's sense of dignity, independence, choice, individuality and privacy;
- ◆ to provide a means for the intellectual, psychosocial and spiritual growth of residents;
- ◆ to promote a homelike ambience for each resident that collectively produces and encourages a neighbourhood like environment;
- ◆ to promote social interaction, engagement, mobility and improved health for residents
- ◆ (Bond and Fiedler 1998)

While these goals are in line with the values of the 'complete community' model described within Chapter 5 of this thesis, they focus upon the needs of residents. The contribution of the current work lies in extending this model to reflect the concerns of all the main stakeholders.

A potential way forward is offered by Stanley and Reed (1999), who, in a volume dedicated to an analysis of institutions providing care, suggest that the characteristics of institutions are the responsibility of society as a whole rather than simply the individuals involved. They identify a number of key themes which they suggest are essential to an understanding of how to change the nature of care institutions, including the need for re-distribution of power, the need to trace the relationship between individual and institutional values, the importance of creating an ethos or culture of care which is open and supportive and the need to recognise ways in which implicit and explicit models of care impact upon practice.

As a way forward, the authors propose a system of ethical audit involving both internal and external regulators. Ethical audit is defined as *'the adoption of both a philosophy and processes which will enable all stakeholders in the life of the institution to contribute to the maintenance of acceptable standards'* (Stanley and Reed 1999 p 116). The process involves two key stages: an investigation of the values in an institution and an exploration of how those values are manifested in practice. This should then lead into an explicit agenda for change.

The authors are quick to acknowledge the challenges involved in undertaking ethical audit. However, they do not really consider the crucial question of where the motivation to engage in the process will come from. After Goffman (1987), an important theme which they return to several times, is that many institutions are largely self-contained and have limited interactions with the outside world. In such a context it is easy for the language and customs of the institution to become entrenched. This suggests that an important first step should be to develop links with local communities and relatives could provide an important resource in this respect. A further challenge, readily acknowledged by the authors, is the potential for any kind of scrutiny and debate about care standards to have a demoralising effect on staff, with potentially devastating consequences. These challenges must be taken into account in planning developmental work of this nature.

Limitations of the existing body of knowledge and areas for further research

Having considered the findings of the current research in light of the literature to date, it is possible to identify a number of areas requiring further empirical investigation. An important limitation of the body of literature which has informed this discussion is the dearth of research examining nursing home admission in the UK, with most work originating from the US and Canada, the Scandinavian countries and Australia. This may be significant given the operation of different systems for allocating and funding placement across these countries which are likely to impact upon the experiences of older people and family caregivers. However, there is remarkable consistency in the findings of studies across countries.

Overall, examination of the body of research evidence to date reveals a limited focus on the perceptions of older people and family caregivers themselves, particularly those with any degree of cognitive impairment. In particular few studies explore and compare the experiences and perceptions of nursing home admission from the viewpoints of all the major stakeholders involved. There are few accounts of the experiences and aspirations of staff working in care homes to the extent that they are almost an invisible workforce. The views and experiences of minority groups such as gay and lesbian older people and older people from ethnic minorities are notable by their absence and there are few explorations of the way in which gender might impact upon experiences. Very few studies consider the experiences of couples who both live in care homes.

In spite of these limitations, the literature reviewed does reveal a remarkable consistency in relation to the experiences of family caregivers around the time of admission. However, studies which examine the organisational culture within nursing homes are few and, on the whole, do not consider the role of family caregivers in shaping this culture. Although the present study has produced important new insights, particularly in the latter area, all of the above would benefit from further empirical study.

Theoretical perspectives

In terms of the development of theory in relation to the needs of older people living in care homes and their families, a number of conceptual and theoretical frameworks are described within the literature. However, these are mostly derived from research carried out in settings other than care homes and there is a need for more explicit empirical testing of a range of theoretical ideas within this setting. Importantly, much of the literature reviewed, both during the initial stages of the research, and more recently, was devoid of references to theoretical or conceptual frameworks which might provide a basis for education, research and practice in this field. In terms of mid-range substantive theories, notable exceptions include Bower's (1988) typology of family caregiving, Nolan *et al.*'s (1996a) temporal model of caregiving, and Nolan *et al.*'s (1996b) typology of admission types. The

processes suggested by Nolan *et al.* (1996b) for conceptualising experience prior to the move to a nursing home as a positive choice, that is: anticipation; participation; information; and exploration also provide a useful framework within which to explore family caregivers' experiences of nursing home entry.

A number of studies have attempted to apply mid-range theories developed in other contexts to the experiences of older people and their relatives in relation to nursing home entry. These include the notion of caregiving as career (Cosbey 1994, Aneshensel 1995, Murphy *et al.* 1997, Ross *et al.* 1997), models of life crisis (Oleson and Shaddick 1993) and locus of control theory (Morgan and Zimmerman, Chen and Snyder 1996). However, with one exception, these theories are only useful in explaining certain aspects of the phenomenon of interest. An important potential exception is the formal mid-range theory of transitions described by Schumacher and Meleis (1994) and Meleis *et al.* (2000). This presents a comprehensive framework which recognises the significance of transitions for health and attempts to encapsulate characteristics and indicators of healthy transition processes in order to suggest appropriate nursing interventions. This framework will now be described in some detail in order to consider both how it might illuminate the findings of the current study and to explore how the present findings might extend and refine Meleis' theory.

This theory, in contrast to others described previously (e.g. Bowers 1988, Nolan *et al.* 1996b), is formal rather than substantive: that is, it is not concerned with a particular instance of a transition, i.e. nursing home entry, but rather focuses on transitions more generally. This distinction between substantive and formal theory is often a subtle but nevertheless an important one. This was noted by Glaser and Strauss (1967) in the following way:

'By substantive theory we mean that developed for a substantive, or empirical, area of sociological inquiry such as patient care... by formal theory we mean that developed for a formal, or conceptual, area of sociological inquiry, such as stigma'.

(Glaser and Strauss 1967 p32)

Both substantive and formal theories are considered 'mid-range', that is they fall between the 'minor working hypothesis of everyday life and the all inclusive grand theories' (Glaser and Strauss 1967 p55), but they differ in terms of degree. For example, in relation to their own seminal work on dying as a status passage Glaser and Strauss (1967) stress that the original theory was substantive (i.e. its' primary focus was on dying rather than status passage). In this context a formal theory would have concentrated on comparing differing types of status passage (one of which may have been dying) rather than on a single type of status passage.

However, it is conceptually quite appropriate to compare substantive and formal theories as they often shade into each other. The purpose here, therefore, is to consider Meleis *et al's.* (2000) formal theory of transitions and explore how, and if, the substantive theory developed in the present study could help to augment it or vice versa.

The mid-range theory of transitions

It has been suggested that assisting individuals to manage life transitions is a key function of nursing (Schumacher and Meleis 1994, Meleis *et al.* 2000) with transition being defined as:

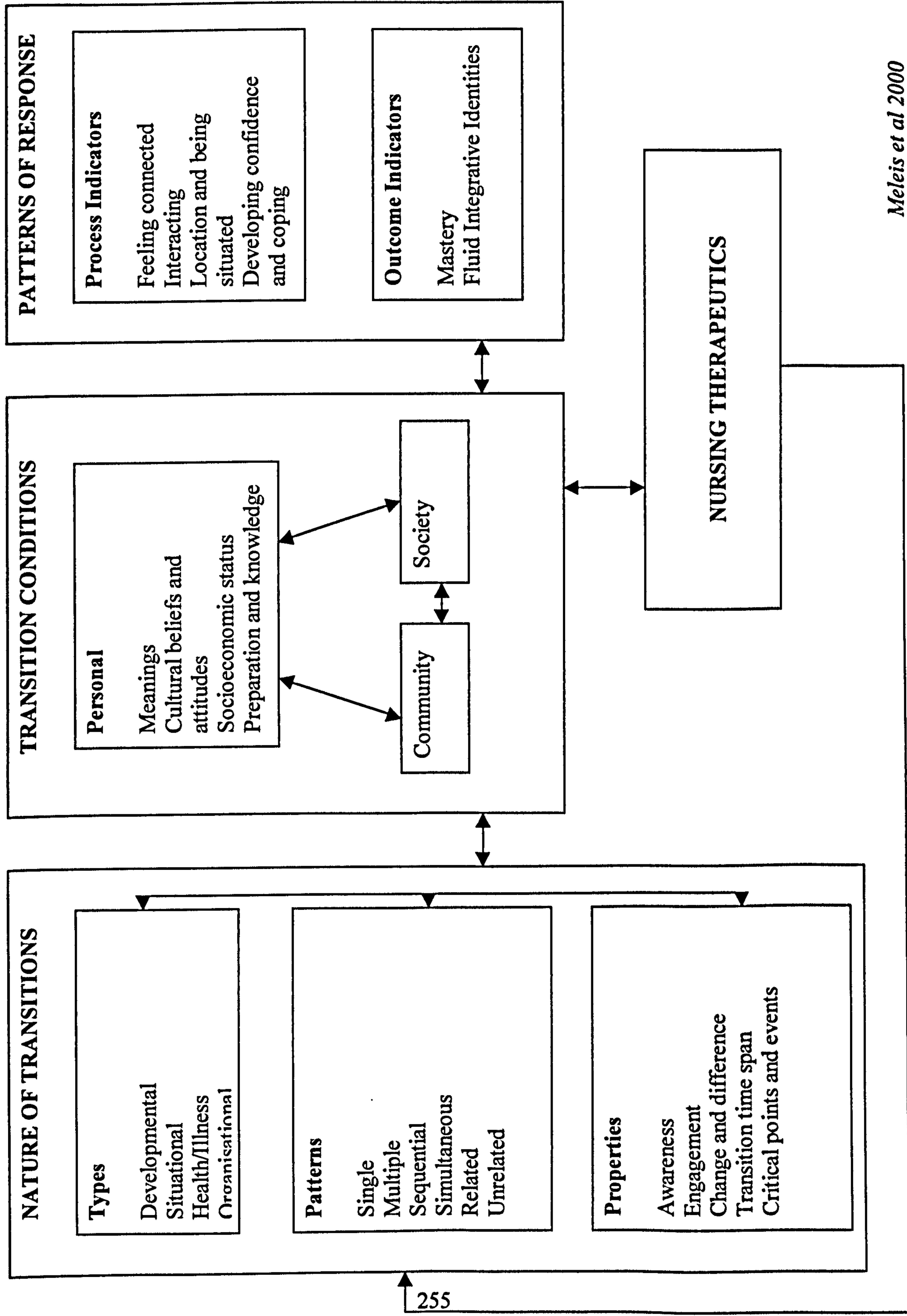
'The passage or movement from one state, condition or place to another.'

(Chick and Meleis 1986 page 237)

The rationale for considering this an important area for nursing and social care is that people undergoing transition tend to be more vulnerable to risks that may affect their health and well-being.

Transitions often require an individual to incorporate new knowledge, to alter behaviour, and therefore to change the definition of self in social context (Meleis 2000, Wilson 1997). The challenge for nurses and others involved in supporting individuals undergoing transition is to understand transition processes and to

Figure 6.1 Model of Nursing Transitions



develop interventions which are effective in helping individuals to regain stability and a sense of well-being (Schumacher and Meleis 1994). Meleis and colleagues have completed a number of empirical studies examining a range of transition experiences including becoming a mother (Sawyer 1996, 1999), experiencing the menopause (Im 1997, Im and Meleis 1999), developing chronic illness (Messias 1997) and taking on a family caregiving role (Schumacher 1996). The findings of these studies have led them to develop a formal middle-range theory of transitions. The three domains of this theory: the nature of transitions, transition conditions and patterns of response are illustrated in Figure 6.1. The key components of the model and the ways in which findings of the current study relate to each element are presented in Table 6.2.

Table 6.2 Elements of the Model of Nursing Transitions and their relevance within the current study

ELEMENT	DESCRIPTION/ IMPLICATIONS	RELATIONSHIP TO CURRENT STUDY
NATURE OF TRANSITIONS		
Types: Developmental Situational Health/Illness Organisational	Nurses regularly encounter four main types of transition in their work with individuals and families. <i>Interventions need to be tailored to the type of transition</i>	All of these transition types may affect family caregivers involved in assisting an older person to relocate to a new long-term care environment.
Patterns: Single Multiple Sequential Simultaneous Related Unrelated	Transitions are commonly patterns of complexity and multiplicity, with individuals experiencing more than one type of transition concurrently	Many relatives were dealing with, not only the situational transition of a change in the nature of the relationship with a close family member, but also with transition in their health status, often as a consequence of their own ageing or ill health. The result was that they were commonly dealing with a whole series of stressors and demands simultaneously, not all of which were necessarily related to the transition.

Table 6.2 Elements of the Model of Nursing Transitions and their relevance within the current study (cont.)

ELEMENT	DESCRIPTION/ IMPLICATIONS	RELEVANCE TO THE CURRENT STUDY
Properties:	Meleis <i>et al.</i> describe a number of universal properties of transition or commonalities which are evident across the range of types of transition. <i>Consideration of these properties in relation to a particular transition is especially important in suggesting which nursing interventions are appropriate.</i>	
Awareness	Level of awareness is related to perception, knowledge and recognition of a transition experience	Initially most relatives were unaware of, and therefore unprepared, for the traumatic nature of the transition. Later most experienced it as painful and emotional. However, few had been encouraged to consider or talk about their own experiences. There was a lack of acknowledgment that relatives were themselves undergoing a life transition.
Engagement	The degree to which a person demonstrates involvement in the processes inherent within the transition. Indicators include seeking out information, using role models, actively preparing and proactively modifying activities.	Relatives varied in their degree of engagement in the process. Those who were proactive in seeking information tended to have more positive experiences.
Change and difference	Transitions result in changes in role, identity, relationships, abilities and patterns of behaviour	Relative described changes in role, relationships and patterns of behaviour. Efforts to <i>maintain continuity</i> suggested attempts to retain their caregiving identity within the new context. New abilities related largely to strategies for negotiating care with staff in order to <i>ensure best care</i> .
Transition time span and critical points and events	The process of transition takes place over time, commonly involves development, flow or movement from one state to another and can often be divided into a series of stages or phases. Critical points and events are associated with increasing awareness of change and more active engagement with the transition process.	Participants described their experiences in terms of three main stages: <i>making the best of it</i> (involving decisions about long-term care choices), <i>making the move</i> (involving the physical transfer and getting to know the individuals and routines within the new environment), and <i>making it better</i> , which involved them in identifying a new caring role, monitoring care and maintaining their relationship with the older person. Critical events were most commonly associated with the decision to seek long-term care and with negative events within the new care environment that caused them to reflect upon whether they had made the right decisions.

Table 6.2 Elements of the Model of Nursing Transitions and their relevance within the current study (cont.)

ELEMENT	DESCRIPTION/ IMPLICATIONS	RELEVANCE TO THE CURRENT STUDY
TRANSITION CONDITIONS	Wide variations occur among individuals, families or organisations in transition. <i>An appropriate framework for assessment needs to capture this variation in order to reflect transition experiences</i>	
Personal:		
Meanings	The subjective appraisal of an anticipated or experienced transition and the evaluation of its likely effect on one's life	Due to the overall lack of anticipation of placement as a life event few relatives had given prior thought to its likely impact.
Cultural beliefs and attitudes	When stigma is attached to a transition experience the expression of emotional states related to the transition may be inhibited	Negative perceptions of nursing homes were held almost universally prior to the need to consider long-term care options. For most participants, these perceptions contributed to feelings of guilt and are likely to have inhibited relatives in expressing their own needs.
Socioeconomic status	Socioeconomic status has an important impact on transition experiences	Older people and their relatives who were able to supplement social services fee levels, and those who were able to pay the full cost of nursing home care and therefore bypass the need for social services assessment, were able to choose from a wider range of accommodation. Low socioeconomic status often contributed to the experiences of being <i>out of control</i> of events.
Preparation and knowledge	People undergoing transition may or may not know what to expect and their expectations may or may not be realistic. As a transition proceeds, expectations may prove to be incongruent with unfolding reality. <i>Extensive planning helps to create a smooth and healthy transition</i>	Most relatives were <i>in the dark</i> in relation to what to expect in terms of levels of service and their own involvement following the move. Expectations of rehabilitation services within the home were usually unmet. Many participants were unaware whether a detailed assessment of their relatives needs had taken place. Where relatives were involved in assessment, experiences were usually more positive.

Table 6.2 Elements of the Model of Nursing Transitions and their relevance within the current study (cont.)

ELEMENT	DESCRIPTION/ IMPLICATIONS	RELEVANCE TO THE CURRENT STUDY
<p>Community conditions</p>	<p>The availability or lack of availability of community resources can facilitate or inhibit transitions. <i>Assessment of community conditions and adaptation and supplementation where possible can facilitate a smooth transition.</i></p>	<p>Community resources include support practitioners and from friends and other family members, and characteristics of the care home environment which support a smooth transition. Participants within the study derived support from a range of sources external to the nursing home. In particular, family members and friends frequently provided a listening ear and shared responsibility for continuing to support the older person living in the care home through regular visits. Health and social care professionals, particularly social workers were identified as a source of valuable support. However, just as frequently, participants described a sense of isolation and a perception that they were <i>working apart</i>. The type of community model which was dominant within a nursing home had important implications for the experiences of relatives, residents and staff.</p>
<p>Society</p>	<p>The wider sociocultural environment shapes the transition experience. <i>Awareness of the sociocultural context of a transition can enable nurses to develop interventions at the group, community and societal level.</i></p>	<p>Relatives felt <i>under pressure</i> from negative images of care homes portrayed in the media. Relatives were aware of the poor working conditions and lack of training for staff working in care homes. Staff within some homes felt isolated, lacking in support and recognition</p>

Table 6.2 Elements of the Model of Nursing Transitions and their relevance within the current study (cont.)

ELEMENT	DESCRIPTION/ IMPLICATIONS	RELEVANCE TO THE CURRENT STUDY
<i>INDICATORS OF HEALTHY TRANSITIONS</i>	Include both process and outcome indicators. Process indicators are helpful in identifying whether clients are moving in the direction of health or towards vulnerability and risk. <i>Ongoing assessment is therefore crucial in facilitating nursing interventions to promote healthy outcomes.</i>	Suggests the importance of on-going and regular assessment and care planning in relation to the needs of both older people and their close relatives. This was absent for most of the relatives within the study.
Process Indicators:		
Feeling connected	Concerned with making new contacts and continuing old connections. Feeling connected to health care professionals who can answer questions and with whom they feel comfortable. Also requires continuity in relationships between health care providers and patients/clients.	This was reflected in the importance attached by relatives in the current study to continuity in staffing and consistent allocation of individual carers. Relationships with individual members of staff were important, both to residents and relatives. Maintenance of the relationship between the relative and the older person was an important element of <i>maintaining continuity</i> . Being able to continue the relationship in the same pattern as before or re-establishing a prior pattern was an important outcome for relatives within the current study: however, few had managed to achieve this.
Interacting	Through interaction, the meaning of the transition and the behaviours developed in response to the transition are uncovered, clarified and acknowledged. <i>Through interaction, a context is created in which self-care and caregiving can take place effectively and harmoniously.</i>	The importance of effective communication at all stages of the transition was a key finding. The potential consequences when communication was less than effective were apparent in relatives' experiences of <i>working in the dark, feeling unsupported</i> and <i>working apart</i> from care staff. The effectiveness of communication had important implications for the type of relationship which developed between relatives and care home staff.
Location and being situated	Involves understanding the new life by comparing it to the old. Being situated involves finding justification for how or why they came, where they are and where they have been.	Participants within the current study varied in the extent to which they had reached an understanding and acceptance of how they came to be in their present situation. Those who felt they had been able to maintain control of decisions, had been able to take their time in planning the move and had been well supported appeared to adjust more easily.

Table 6.2 Elements of the Model of Nursing Transitions and their relevance within the current study (cont.)

ELEMENT	DESCRIPTION/ IMPLICATIONS	RELEVANCE TO THE CURRENT STUDY
Developing confidence and coping	<p>The extent to which there is a pattern indicating that the individuals involved are experiencing an increase in their level of confidence.</p> <p>Demonstrated by an understanding of the different processes inherent in diagnosis, treatment, recovery and living with limitations, in the level of resource utilisation and in the development of strategies for managing. Involves a sense of wisdom resulting from lived experiences.</p>	<p>The current study provides evidence that the actions of health and social care staff are important influences on the extent to which relatives develop confidence and coping skills. Where relatives are provided with up-to-date and relevant information, are encouraged to recognise their own expertise and to contribute to an older person's care in the way that both they and the older person are comfortable with, then confidence in their ability to cope within the new environment developed rapidly. However, where such support was not forthcoming, and relatives lacked the inner resources to recognise their own abilities, then they frequently failed to reach this level of well being.</p>
Outcome Indicators:		
Role mastery	<p>A sense of achievement of skilled role performance and comfort with the behaviour required in the new situation.</p> <p>May be represented by individuals starting to make their own decisions and by taking control of the situation.</p>	<p>The extent to which family members demonstrated 'mastery' was variable and to a degree dependent upon whether care staff facilitated or impeded their involvement in direct care-giving activities and in decision-making. Many remained uncertain about their abilities to meet the needs of their relative within the new care environment. Others were more confident that skills developed over many years were transferable to the new setting and were able to resist staff efforts to 'take over'. Observations within the case study settings suggested limited attempts by staff to encourage relatives to recognise their own 'mastery' of the role of family caregiver within the nursing home.</p>
Fluid Integrative Identities	<p>Transition experiences have been characterised as resulting in identity reformulation. Perspectives become 'bicultural' rather than 'monocultural'</p>	<p>Development of a bicultural perspective was reflected in participants' attempts to understand the pressures on staff, trying to see the situation from their point of view. A further application of this idea could lie in the relatives' ability or willingness to create a life outside of the home.</p>

As can clearly be seen, there are numerous points of connection between the formal theory of Meleis *et al.* (2000) and the present substantive theory, suggesting that the notion of transitions provides a broadly appropriate framework within which to locate the current findings. The key question is whether it provides a complete framework or if in fact the present theory could suggest ways in which that of Meleis *et al.* (2000) could be extended.

The model of nursing transitions: extending its application to the care of relatives experiencing nursing home entry

As noted above, the model of nursing transitions as first described by Schumacher and Meleis in 1994 and modified in later writings (Schumacher *et al.* 1996, Meleis *et al.* 2000), provides a useful framework for considering the findings from the two phases of the current study. In particular, the model's focus on transition types, conditions and outcomes has allowed a detailed consideration of the factors which might facilitate or inhibit a successful transition to a new 'healthy' state. However, as with any developing mid-range theory, application to diverse situations is necessary in order to adjust and adapt the model to fit a range of circumstances. Comparing the model with the findings of the current study suggests a number of important omissions and an insufficient emphasis within certain important dimensions of the framework.

A significant limitation of the Meleis theory model for considering transitions to a nursing home setting (and thereby potentially other forms of transition) is the failure to acknowledge the reciprocal inter-relationships between process and outcomes for all involved. Analysis of data from both phases of the current study revealed the sterility of attempting to understand and explain family caregivers' experiences of nursing home entry without also considering the experiences of older people and staff within care homes. The experiences of older people and family caregivers are shaped by the complexity of decision-making in this context and are influenced by a range of perceived demands and responsibilities. The move to a nursing home creates a series of stressors and demands for older people and their caregivers. Staff within nursing homes also experience demands and stressors. Yet the model of nursing transitions seems to under-emphasise this

interplay, and rather portrays the professionals (nurses) as relatively detached 'experts'. Thereby, the model fails fully to acknowledge the significance of 'emotional labour' - the emotional component of all nursing work and specifically work in a care home.

As suggested above, therefore, another important limitation of the model is that it tends to treat recipients of nursing interventions as passive and as if they have little potential to contribute to their environment or to influence their own destiny. The potential consequences of this perception are tellingly summarised by Stanley and Reed (1999):

'The vivid images that we have of recipients of charity, from frail older people to vulnerable children, do not include any notion that they might be giving something back to their benefactors – the traffic of kindness is entirely one way...This denial of reciprocity does a number of things. It diminishes the service-user as an active agent and portrays him or her as entirely passive. This passivity is then taken as a rationale for privileging the expert's view, as this inability to act is taken as evidence of incompetence to act. A further idea is then brought into play, about the way in which the service-user should be grateful to the practitioners for what they are providing as he or she would not be able to cope without this assistance. Any rejection of care is then viewed not just as a difference in opinion, but as a moral failing – service users are 'ungrateful' or 'awkward' or 'demanding'.

(Stanley and Reed 1999 p 65).

However, while nurses have a large part to play in creating the conditions in which relatives feel able to participate, encouraging relatives to recognise their potential for enhancing life within the home is more than simply a nursing responsibility. Data from both phases of the current study demonstrate that relatives can play an important role in enriching the lives not only of their own relative, but of other residents, their families and staff as well. In order to improve the experience of relatives following the admission of an older person to a care home they must be prepared to take the initiative and to challenge the status quo. This will need some adaptation on the part of staff who have been used to operating with a different

mindset, one which sees relatives as potential adversaries, or in some cases as customers. Family members who wish to maintain a close relationship with the older person need encouragement to see the care home as a second home where they receive a warm welcome, but a welcome which extends beyond that offered in the 'cosmetic community'. Therefore, the most positive experiences seem to result when relatives perceive that they too have a larger part to play in 'making it work'.

The significance of organisational culture within care homes, in particular models of care, for the experiences of service users emerges clearly from both phases of the study and finds support within the literature. This aspect is insufficiently emphasised within the model of nursing transitions for it to adequately represent key factors shaping relatives' experiences of nursing home entry. This therefore raises questions, which at this point it is not possible to answer, as to whether the relative absence of the above reciprocal and interactive dimension is an element of Meleis *et al.*'s (2000) theory that requires further exploration in relation to other forms of transition.

Summary

While many of the findings and impressions from the current study are consistent with those from earlier work, they elaborate and extend upon prior findings in important ways. Unlike previous studies, this thesis combined a detailed description and analysis of relatives' experiences with an exploration of nursing home culture and practices through focused case studies. This adds a further layer of understanding to the dynamic nature of these experiences. Moreover, the approach adopted facilitated an exploration of the experiences and perceptions of all stakeholders, thereby producing a more complete analysis of the factors which shape relatives' experiences in this context. From this analysis it is clear that practitioners in health and social care have enormous potential to influence whether relatives experience home entry as a positive choice. Unfortunately, current practice seems to result more frequently in relatives either resigning themselves to the decision, or bitterly regretting the choices they have made.

However, another important element of the present study is that it sounds a more optimistic note in that even where relatives have negative experiences during the decision-making phase, there is evidence to suggest that these can be compensated by positive experiences within the new care environment.

The creation of appropriate cultures of care or *community models* as they are termed here, has the potential both to enhance the overall transition experience, and to create more positive images and perceptions of care homes, which in turn should make the process of decision-making easier. Significantly, however, creating a more '*complete community*' extends such benefits beyond the family carer and has the potential to enhance the quality of life of the older person and the quality of the working environment and job satisfaction of staff. The findings of this study therefore suggest that the potentially most appropriate type of community within a care home: has person- and relationship-centred care as a key objective; promotes links with the local community; recognises the importance of valuing and enabling staff; and perceives the potential for growth and development in later life.

Notwithstanding the current policy of community care, population longevity suggests that placing a relative in a nursing home is likely to be an increasingly common experience and should, as several authors have suggested (Aneshensel *et al.* 1995, Nolan *et al.* 1996a, Jack 1998b), be viewed as a normative part of the caring career. One of the key aims of the present study was better to understand this experience in order that, if necessary, it could be improved. One of the main advantages of mid-range theories is that they lie closer to the empirical world than do the abstract and more remote 'grand theories'. They are therefore hopefully more accessible conceptually to those who might be interested in them and are also more directly applicable to real world situations. True to this sentiment this thesis concludes by considering the implications of the study for policy, practice, education and future research.

CHAPTER 7. CONCLUDING COMMENTS AND DEVELOPMENTAL IMPLICATIONS

This thesis has been constructed during a period of growing interest in the health and social care needs of older people in general, and of those requiring continuing care in particular. Since I began the research in 1997, a series of policy documents and resultant legislation have focused attention on the support available to older people and family caregivers to enable them to avoid residential or nursing home care for as long as possible. Concurrently, separate initiatives have focused upon funding for long-term care and the need for equitable standards across continuing care environments. This chapter begins with a brief consideration of these initiatives before outlining the developmental implications of the research.

The current policy context

In Chapter 1, I described some of the key themes in government policy which have shaped the experiences of family caregivers during the final stages of the caregiving trajectory. These include an emphasis on enabling people to be cared for within their own communities, often involving increased reliance on family and friends, and a concern to reduce the cost of care to public funds.

In 1997, in view of mounting concerns over the costs of long-term care and the quality of care in some homes, the Labour government set up a Royal Commission on Long Term Care under the chairmanship of Sir Stewart Sutherland. The aim of the Commission was to examine the short- and long-term options for a sustainable system of funding of long-term care for older people, both in their own homes and in other settings. Recommendations relate principally to funding arrangements, with a key proposal that nursing and personal care should be centrally funded for anyone needing long-term care (The Royal Commission on Long Term Care 1999). The Commission recommended that accommodation and food costs should continue to be means tested. A number of recommendations related to the quality of care in nursing homes and a National Care Commission was proposed with a

remit to monitor implementation of the new system, provide information and monitor standards. Other recommendations included that nurses should be more involved in assessments for entry to care homes and importantly that services for ethnic minority users should be improved. The Commission's report was generally well received by service user groups and practitioners, but the key message that care should be centrally funded was considerably weakened by the production of a minority report written by two of the commissioners who disagreed with this important proposal. Their argument was that central funding for personal care would do very little to raise the quality of care within the majority of care homes and that resources would be better directed towards intermediate care (Lipsey 2001).

The government's response to the report is included as an Annex to the most recent blue-print for the NHS - the NHS Plan (DoH 2000). Significantly, the government chose not to implement the recommendations of the Commission in full. While they have accepted the proposal that nursing care should be free at the point of delivery, charges for personal care will continue to be means-tested along with accommodation costs. In financial terms these changes are likely to have the greatest impact for those residents who pay the full cost of nursing home care. The need for nursing care will be assessed by qualified nurses within three bands, with a maximum payment of £110.00 per week. The eligibility criteria and the short timescale for implementing the new arrangements have been widely condemned (Coombes 2001). Experts have also expressed concern that very few older people will be assessed as being in the highest band as a result of limits on the total budget available. In reality, the payments are unlikely to have much impact for older people who are responsible for funding their long-term care and their families, given that the average weekly cost of nursing home care at time of writing was £350.00 (Laing and Buisson 2000).

New proposals for intermediate care, which were also outlined in the NHS Plan, are aimed partly at avoiding crisis admissions to long-term care by providing a period of on-going assessment and rehabilitation. It is anticipated that a proportion of this intermediate care will be provided in care homes, and this is

likely to have an effect on the dynamics of care within homes. This also raises questions about the preparation of staff within care homes to provide intermediate and rehabilitative care.

In March 2001, the government launched the National Service Framework (NSF) for Older People, which aims to improve and standardise the quality of care for older people in a range of care environments (DoH 2001). The NSF for older people embraces the principles of dignity, autonomy and independence within its recommendations and is likely to make an important impact on care at the interface between acute, intermediate and continuing care. The likely effects of implementation of the framework on care practices within care homes in the private and voluntary sectors are more difficult to estimate.

For those needing nursing home care, initiatives aimed at standardising structure and process within care homes are being established at time of writing. The Care Standards Bill (2000) introduces a range of minimum standards which proprietors and managers of care homes must achieve from April 2002. These include minimum standards for building specifications, room occupancy, staff training and management. However, there are concerns that many homes within the independent and voluntary sectors will be forced out of business as a result of these requirements, resulting in compulsory relocation for some residents. This is likely to have important implications for residents and their relatives who have settled in a particular home.

All of these changes and initiatives are likely to impact upon the experiences of older people and family caregivers around and beyond the time of admission to nursing home care. The introduction of minimum standards, together with a national body with responsibility for overseeing their implementation should, in the longer term, improve experiences of admission to, and life within a care home. However, in the absence of adequate levels of government funding, some homes will inevitably close resulting in disruption and trauma for the residents, their relatives and staff involved. In reality, inequalities and inconsistencies in standards of care are likely to persist, at least for the foreseeable future. The

current research has revealed how the complexity of funding arrangements for long-term care in the UK results in high levels of anxiety for older people and their families about whether they will be able to afford to move into, and remain at, the nursing home of their choice. The government's recent decision not to implement the findings of the Royal Commission in full and to fund centrally only the cost of nursing care rather than personal care for residents of care homes in England is unlikely to alleviate this situation (DoH 2000). Further confusion is likely to result from the decision of the Scottish parliament to fund personal care as well as nursing care.

The changing context of continuing care outlined so far in this chapter is resulting in uncertainty for everyone with an interest in the care home sector, most importantly residents, their families and staff. However, the media attention accompanying recent changes in policy should gradually result in a greater level of awareness of the experiences of older people living in care homes amongst the general public. In (perhaps optimistic) anticipation that this enhanced public awareness, and potentially increased sense of public responsibility, will create the conditions necessary for change, the developmental implications of the current research will now be considered.

Developmental implications

This study has expanded from my original intentions to explore family caregivers' experiences around the time of nursing home entry. While these perceptions and feelings remain central to the developmental implications suggested by the research, my early investigations hinted that it would be inappropriate and artificial to separate the experience of decision-making and admission to care from the ongoing experience of maintaining a role in the older person's life. I was also persuaded by the need to locate relatives' experiences within the context of care and perceptions of all involved, in the pursuit of meaningful insights. As a consequence, the implications of the research relate as much to the challenge of creating appropriate cultures of care within care homes as to the challenge of easing the transition.

The following developmental implications are practical suggestions for improving the experience of older people and their relatives needing long-term care. However, these should be considered in the context of the need to ensure that admission to a nursing home can be construed as a positive choice. This requires action at a number of levels: for example staff working in nursing homes must seek to create a culture of care which values inter-dependence, ensures that care is person-centred and encourages and enables reciprocity within relationships. This will require that appropriate support mechanisms for staff are in place, including effective leadership, appropriate training and clinical supervision. There are also implications for relatives themselves to recognise their potential for making a difference to care experiences within nursing homes and to take the initiative in this respect.

Close collaboration between researchers, educators and care providers is necessary to ensure that care staff are aware of the needs of relatives as well as residents, and their potential role in meeting these needs. Changing current practice will also require a shift in attitudes to encourage health and social care practitioners to value the contribution of relatives and friends. Shreeve for example (2001) calls for older people and family caregivers to be seen as a positive resource suggesting that, while they often have problems, they are also part of the solution and can contribute to the planning and delivery of care for others. There is likely to be an increasing role here for service user organisations such as the Relatives and Residents Association, which provides information and support to relatives and residents of care homes and campaigns for improved standards of care.

Findings of this study confirm that the way in which the transition to nursing home care is managed exerts a significant effect on the quality of life for older people and their family carers and suggest important developmental implications for practice within this field. In particular, the findings suggest that at each phase of the transition, practitioners should be aiming to:

- ◆ work in partnership with older people and their family caregivers;

- ◆ be aware of the range of pressures which family caregivers are experiencing and aim to minimise these pressures wherever possible;
- ◆ ensure that older people and their family caregivers are well informed;
- ◆ enable older people and family caregivers to maintain control over events and decision-making;
- ◆ ensure that older people and family caregivers are supported, both in practical and emotional terms.

Under a series of sub-headings, principal recommendations for improving the experience of older people and family caregivers are followed by practical suggestions for achieving each aim which draw both on the findings of the current research, and on the wide literature reviewed for this study. Finally, implications for further research are suggested.

Making decisions about long-term care and preparing for the move

Moving into a residential or nursing home is a major life event with important repercussions for an older person and their close relatives. It is therefore essential that older people in need of continuing care and their family caregivers should be appraised of all the options open to them. Many family caregivers interviewed for this study were unaware that a package of care to enable their relative to remain at home may have been a possibility. Others found the lack of flexibility in community services a barrier. However, the number of participants who perceived that they were told that there was no option to their relative moving into a nursing home suggests either a breakdown in communication, or a pervasive ethos of paternalism within health and social services. Taken together these findings suggest that older people and their family supporters are frequently rushed into decision-making, often with important consequences for the well-being of their relationships and their future quality of life.

The research reported here suggests that the development of service models aimed at easing the transition between care environments within the context of systematic evaluation is timely. For example, nurse-led intermediate/transitional care units may have the potential to ensure comprehensive assessment of an older person's needs, appropriate choices about long-term care options and preparation for the transition to a new care environment. Alternatively, intermediate care packages at home which are sufficiently flexible to ensure their acceptability to older people and their families, might reduce the sense of 'crisis' and enable families to make the most appropriate decision for all involved. What is abundantly clear from this research is that an acute hospital ward is an inappropriate setting for decision-making about long-term care.

Finding an appropriate nursing home placement represents a further challenge, one which some relatives find overwhelming. In particular, relatives' lack of awareness of 'what they need to know' creates a major obstacle to decision-making. Health and social care workers who regularly support older people and their families in making decisions about long term care choices should be prepared to guide prospective residents and their families in relation to points to consider when choosing a nursing or residential care home. Relevant staff include social workers and home care managers, community nursing staff and hospital based social work and nursing staff who regularly care for older adult. Written 'checklists' of possible criteria should also be available through local branches of organisations representing older people and via the Internet. Managers of care homes should also consider making such guidance available to prospective residents and their families.

Few of the relatives in this study were aware of the existence and availability of inspection reports produced by the Registration and Inspection Unit of the local health authority: and yet such reports could provide invaluable information for those faced with the responsibility to choose between homes. To maximise the potential value of inspection reports as a resource for relatives, these should be summarised in an accessible format and readily available to prospective residents and their families. Reports should also be available via the Internet. Home

managers should consider making copies of the most recent report available to prospective residents and their families. The use of telematic systems, to support family caregiving and decisions about long-term care, geared to local services and facilities, have evaluated positively (Hansen et al 2000) and should be developed within the context of a wider evaluation.

The finding of this study that many older people needing long-term care are unable to visit a prospective home prior to moving in suggests that decisions are frequently made on the basis of insufficient information. This places even more responsibility on relatives charged with making the final choice of home. Even though most home managers suggest that admission is for an initial trial period, in reality there are a number of barriers to between-home transfer, in particular the desire to avoid yet another upheaval. Older people and family caregivers planning admission to a home should therefore be enabled to spend time at the home before making a final decision wherever possible. At the very least, the prospective resident should be able to visit the home prior to admission and spend a day there. Family caregivers should also have the opportunity to spend an extended period of time at the home if they so wish. Creative approaches to funding such opportunities, including the cost of accommodation, meals and transport, should be explored between local authorities, home managers and voluntary organisations.

A consistent finding of this study and other contemporary research is that older people and their relatives are unprepared for the reality of nursing home life. This suggests that nursing home managers should better prepare the older person contemplating a move, and their family, in relation to what to expect following admission, both in terms of the facilities and therapies which are likely to be available. Fee levels and costs for additional items of service should also be discussed. Providers should make their policies towards relatives explicit and potential areas for family involvement should be highlighted and agreed, preferably prior to the admission itself. The use of care contracts specifying the contribution of care home staff and family members to an older person's care should also be explored and evaluated.

Providing appropriate care environments

The findings of this study suggest that an appropriate care environment for older people in need of nursing home care is one which mirrors a domestic communal setting and allows close relationships to develop and be maintained between residents, their relatives and staff. This suggests that homes should be small in size (a maximum of approximately 30 places) or divided into small living units to mirror a domestic model as far as possible. The case study research suggests that the layout of the home which most effectively supports relative involvement includes access to a choice of communal areas in close proximity to each other and close to staff areas. Communal rooms should have sufficient seating to allow visitors and staff to sit close to residents and should include a number of sofas to allow hand-holding and cuddling. Individual bedrooms, sufficiently spacious to allow residents to receive visitors in private are a fundamental requirement to maintaining relationships, particularly for residents with a community dwelling spouse. Proximity to bus routes and level access are important considerations for family members who may themselves be ageing.

The need to ensure links with the local community, both to avoid social exclusion for residents and staff and to support family members is an important insight from the case studies reported here. There is sufficient evidence, both from this study and the wider literature, to suggest that owners and managers of nursing homes should seek wider involvement from members of local communities and voluntary organisations. In particular the potential for League of Friends volunteers to expand their services to care home settings provides an important opportunity. The literature reveals that residents who do not have regular visitors may be disadvantaged, suggesting that the potential for resident 'adoption' programmes involving local volunteers should be explored. Such developments could be the responsibility of activity co-ordinators working in partnership with residents and family members.

Providing appropriate care within care homes

What is clearly apparent from the interviews and case study research is the importance that most relatives attach to their continued involvement in one form or

another, in ensuring the quality of life of their relative. This reflects the findings of a wide range of studies on both sides of the Atlantic. However, such participation is often not actively promoted or facilitated and indeed can sometimes be blocked by staff. In some homes, staff rarely draw upon the expertise of family caregivers in planning and implementing care for residents and do little to enhance the experience of visiting.

Care staff should be encouraged to consider relatives as expert partners in care unless this is contrary to the relative or older person's wishes. Relatives should be involved in the initial assessment of the older person's needs and the proposed plan of care should be negotiated and agreed with all parties. The use of biographical methods of assessment can be particularly valuable and is a practical method for involving family members in assessment and care planning. Where appropriate the development of a written/pictorial biography could be the responsibility of a close family member in association with the older person and the named nurse or key-worker. The biography should remain the property of the older person, and staff and visitors should be encouraged to seek permission before consulting it. However, the use of biographical methods is not without challenges, not least the danger of encouraging residents and family members to recall potentially painful and unresolved memories. It is therefore essential that care staff should receive training in the use of biographical methods before using this approach.

Care staff should ensure that relatives are provided with opportunities to express their own concerns and anxieties around the time of admission and then at regular intervals. Regular, planned review of each resident's needs involving the home manager, named nurse, key-worker, resident and family members would go some way to alleviating relatives' concerns and give them permission to express their views. In order to encourage continued family involvement, staff must recognise and respond to the family's need to be educated about the changing health needs of the resident. Regular review and discussion could provide a vehicle for these activities.

Recreational and educational activities in the care home need to be flexible and adaptable to the changing needs of residents and their family members. Staff members need to be encouraged to perceive a role in supporting and facilitating family visiting both by recognising when families need privacy and joining in with conversations when appropriate. The role of activity co-ordinators can be crucial in both respects and again, community volunteers can be engaged in these processes.

Developing a supportive culture of care within care homes

One of the biggest challenges facing practitioners caring for older people is the need to change entrenched care practices, which are often based on inappropriate attitudes and beliefs. In particular, routinised care practices are the norm in many settings providing continuing care. Nevertheless, awareness is growing that the way to improve care for older people in a range of care environments is to create a culture of positive care which values older people and the staff working with them. The research reported here lends additional evidence to this proposition. Evidence from case studies in three nursing homes suggested that the most positive culture of care was associated with staff who felt well-supported and appreciated, and benefited from effective leadership. The system of ethical audit proposed by Stanley and Reed (1999) and outlined in Chapter 6 of this thesis may provide a whole systems approach to considering and adapting the culture of care within a care home. However, this approach requires further development and systematic evaluation before it can be considered a blueprint for developing practice in this field.

Recent research suggests benefits in identifying the older person's perspective on care-giving and the need for care, and posits that this should be a basic principle of service provision. Such perspectives offer the potential to bridge the gap between nurses' perceptions and the perceptions of older people and their family members in relation to priorities for care-giving. Accessing user views and feeding these views into a change process should therefore be a priority. The establishment of a residents' and relatives' group is an important first step in accessing user views and should be a requirement of registration. Care home staff should facilitate

opportunities for groups to meet regularly. Notes of meetings, including action points will help to ensure that appropriate follow-up takes place. Methods for disseminating information to all relatives, such as a regular newsletter, have the potential to ensure that all relatives feel involved and create ownership of identified problems and solutions.

A growing body of evidence suggests that care assistants, through participation in systematic training programmes, have the potential to positively affect the quality of care in nursing homes (Nolan and Keady 1996, Raja-Jones and Patel 2000). However, training is likely to be more effective in the context of a structured programme, rather than 'one-off'. Training is also likely to be most effective if combined with regular clinical supervision (Brocklehurst 1997).

In terms of identifying their own training needs, nurses working in care homes tend to prioritise clinical nursing issues such as pressure sore risk and medication management and indirect nursing issues such as recruitment and retention of staff, rather than issues relating to quality of life (Morrell et al 1995, Bartlett and Burnip 1998). Lack of preparation for a managerial role has also been highlighted. Programmes of nurse education which aim to prepare nurses to work with older people and their families should include content on the needs of family caregivers, including needs around the time of transition to new care environments. Similarly, in-service training programmes for care assistants and national vocational qualifications in caring should include an explicit focus on the needs of family members. The development of multidisciplinary educational modules in supporting care transitions should also be a priority.

With the closure of continuing care wards in NHS hospitals, many educational centres are developing links with private and voluntary nursing homes in order to offer student placements within this environment (Chilvers and Jones 1997). Indeed there is evidence of potentially beneficial outcomes for residents, staff and students of further developing links between educational centres and nursing homes within the private and voluntary sectors (Lipsitz 1995, Chilvers and Jones 1997). The development of teaching-nursing homes would require the input of

sufficient resources to allow adequate staff preparation. It is also essential to ensure that such developments are carried out in negotiation with residents and family caregivers to ensure that the identity of the facility as the residents' home is not threatened. The roles of clinical nurse specialists and consultant nurses appears to have potential for improving nursing home care experiences for older people and their families but have yet to be systematically evaluated within the UK.

Increasing the ratio of qualified nurses and reducing the reliance on unqualified staff is commonly proclaimed as the solution to the problem of improving care standards within nursing homes. However, the literature reveals a dearth of studies which consider the issue of skillmix within the context of nursing homes. Certainly, few studies have addressed the central issue of whether experiences and outcomes for residents and relatives are affected by the skill mix of the nursing team or whether similar outcomes can be achieved by varying skill mix combinations. There is some evidence to suggest that the attitude of carers and effective leadership may be a more significant factor than staffing levels in determining resident experiences (Pearson *et al.* 1992). In determining appropriate staffing levels, the ratio between qualified nurses and care assistants should allow sufficient opportunities for qualified staff to model direct care-giving.

Areas for further research

A number of areas requiring further research have been alluded to throughout this thesis, both substantive and methodological. In terms of the substantive literature, the limited volume of research carried out in nursing homes within the UK, particularly within the private sector, leaves many aspects of need within this sector under-explored. Experiences of care also warrant further exploration, including the perspectives of residents, relatives and importantly, staff members. While the current study has provided a useful retrospective account of the experiences of relatives in relation to admission to a nursing home, longitudinal study would add to this picture, particularly if the views of all the main stakeholders were traced over time. Case study research to further explore the range and attributes of community models within care homes would provide

additional insight into the full range of influences on care practices and experiences. Furthermore, research is required to explore and evaluate approaches to modifying the community model within a care home to ensure that the needs of all stakeholders are optimally met.

In methodological terms, the need for further application and evaluation of constructivist research methods is discussed in detail in Chapter 6. In brief, my experiences within the current research suggest that constructivist approaches are entirely consistent with research objectives which seek both to illuminate experiences of care and to initiate change processes where change is necessary. However, constructivist researchers must continue to document and report their experiences of using these methods in order to ensure that service users and carers are engaged in ways which have individual benefits as well as creating a catalyst for change.

A workshop co-ordinated by Agenet and The Royal College of Nursing in 1998 (Agenet/RCN 1999) to explore the future of gerontological nursing research identified a number of research topics as crucial to the future development of gerontological nursing practice. These were:

- ◆ **Increasing health expectancy** - developing appropriate models of service delivery, exploring organisational barriers, evaluating technology, understanding individual expectations;
- ◆ **Person-orientated quality of life** - measures that reflect subjective experience;
- ◆ **User and carer involvement** - intergenerational working, accessing the views of people with dementia, methods of determining user expectations;

- ◆ **The effectiveness of therapeutic interventions** - use of artistic expression, accessing the views of people with dementia, methods of determining user expectations;
- ◆ **New roles** - the need for registered nursing, models of service co-ordination, nurse practitioner roles.

Findings of the current study are consistent with the need for further research in all these areas if admission to a care home is to be conceived as a truly positive choice for all concerned.

Final comments

In conclusion, improving the care experiences of older people and their family caregivers around the time of admission to a nursing home and beyond requires action at a number of levels. At societal level, adequate funding for nursing home placement is essential if care standards are to be improved and maintained. Further research is needed to identify the most appropriate arrangements and environments for providing continuing care to frail older people and the economic cost of such care. Furthermore, as a society we need to accept that what goes on in care homes is the responsibility of everyone, rather than being outside of our control. A media campaign, similar to the Dignity on the Ward initiative organised by the charity Help the Aged (Help the Aged 1999), could begin to abolish some of the more shameful practices in care homes and improve the experience of care within a range of care settings.

At an organisational level, individual care home proprietors and managers need to ensure that policies are ‘user’ and ‘family’ friendly and that every opportunity to engage relatives and members of the local community in the life of the home is capitalised upon. It is clear from the findings of this study that some relatives have experienced extremely high standards of nursing home care and sensitive care practices on the part of staff whose role it is to ease the transition. Care homes

need to work together to share good practice and ensure that such exceptional care becomes the norm.

At the level of the individual, care staff must acknowledge and support family relationships, recognising and drawing upon relatives' knowledge of the older person and expertise in their care. It is at this level that change is within the power of every individual practitioner. The findings also have implications for relatives themselves, particularly in relation to recognising their potential to promote positive experiences, both for their own relative, for other residents and staff. Relatives are an important link with the outside world and have the capacity to contribute to the sense of community within a care home.

More than a decade ago, Brody (1986) summarised an important task for all involved in nursing home care as follows:

Families will continue to experience strain, to worry, to be upset and to be sad. They will be anxious about their own aging. They will inevitably (and often legitimately) find things to complain about in the nursing home. They will feel guilt and sorrow. But the task of social policy and of nursing homes is to mitigate such pain to the fullest possible extent rather than to exacerbate an intrinsically painful situation (my emphasis).

(Brody 1986 p12)

The findings of this study suggest that everyone involved in the delivery of care services for older people and their families should hold this as a primary objective. Furthermore, the 'new beginning' of supported family caregiving within the context of a care home holds the potential to enrich family relationships and quality of life. We need to strive to ensure that this potential is fully realised.

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Appendix I Summary of information from a sample of completed Full Needs Assessment (FNA) forms

Description of Full Needs Assessment forms data

Sample: Copies of 49 completed Full Needs Assessment (FNA) forms were obtained from the Family and Community Services Department (FCS). It is not clear whether the forms were randomly or purposively selected or were a sample of convenience.

The assessments were initially grouped according to where the FNA occurred:

8 were initiated in the community

13 were initiated from temporary placements in nursing/residential homes

28 were initiated during a hospital admission

Preliminary analysis suggested 15 broad types of factor precipitating the FNA. These were

- cognitive problems (confusion, dementia)
- other mental health problems (mainly depression)
- breakdown in carer/family relationships
- problems with mobility
- risk of falls
- carer stress (particularly in relation to carers' perceptions of risk)
- self neglect
- visual impairment
- alcohol/drug abuse
- violent/aggressive behaviour
- physical dependence
- medication needs
- illness crisis
- refusing care/social services

No obvious combination of these factors appears to determine the care package recommended on the basis of assessment.

The forms were completed as follows:

i) Community initiated FNA's (n = 8)

3 by social worker alone

1 by social worker and client

1 by carer

1 by client and carer

1 by client (although much of the information on the form was recorded in the third person)

1 was not indicated

All fulfilled the assessment criteria.

Appendix I Summary of information from a sample of completed Full Needs Assessment (FNA) forms

Care package: 5 recommended for care package at home
 2 went to nursing homes
 1 went to EMI nursing home

ii) Temporary placement initiated FNA's (n = 13)

1 by the family of the client
1 by family, client and social worker
8 by the social worker
3 not ticked but probably by social worker

All fulfilled assessment criteria.

Care package: 9 had temporary nursing home placement made permanent
 2 had temporary EMI nursing home made permanent
 1 went into residential care

iii) Hospital initiated FNA's (n = 28)

10 by social worker
7 by carer and social worker
5 by client, carer and social worker
3 by client and social worker
1 by client and carer
1 by carer
1 not indicated

All fulfilled assessment criteria.

Care package: 6 had home care packages
 (1 who tried at home but then went to a nursing home)
 6 went to residential homes
 (1 who tried at a residential home but then went to a nursing
 home)
 5 went to EMI nursing homes
 11 went to nursing homes

Appendix I Summary of information from a sample of completed Full Needs Assessment (FNA) forms

General Points

In general FNA forms are not completed well or comprehensively: this appears to apply particularly to the FNAs carried out in hospitals

A true appreciation of the client's needs is only really gained from the assessor's notes. However, the depth of information included here is variable and if the notes are missing or very brief it is difficult to gain a detailed picture.

It is often difficult from the assessment forms to work out whose views are being presented. To what extent are they able to involve the older person and their carer(s) in the assessment? What are the barriers to involvement? The client's perception of their needs is rarely indicated explicitly, even though there is a specific section for recording this information within the assessment form.

The carers' perception of their relatives needs or their own needs is also rarely indicated explicitly. Only two forms suggested that a separate carer's assessment was carried out. What are the criteria for deciding that a carer's assessment is indicated?

What factors trigger a specialist assessment? These usually provide a much fuller picture.

Risk factors are insufficiently characterised; for example a large proportion of the sample had experienced falls within the previous six months. However, most assessments did not indicate what had caused the fall, how frequently they happened or what the consequences were. In other words, how much of a risk factor is this? Cognitive problems are often described in vague terms such as 'confused' or 'disorientated', again without suggesting specifically the risks for a client within a particular set of circumstances.

We gained an impression that clients who were able to assert their views were more likely to be offered a care package at home. Are older people given enough of a chance to try at home? There seemed to be little evidence that any home assessments had taken place

Some assessments included judgmental statements without qualification e.g. a client with increased alcohol intake with no information of how much she was consuming or how this compared to previous intake. There was no information on what the client's perceptions of the situation were.

Little information is provided in relation to needs associated with ADLs to indicate why or whether a need might become a risk. For example, if a client needs help going to the toilet - is this a risk? In other words there is no indication of how a

Appendix I Summary of information from a sample of completed Full Needs Assessment (FNA) forms

particular combination of factors might suggest a particular type of care package - this seems to be left to the assessor's professional judgement.

There are no obvious criteria for determining when the risk to a client outweighs the client's choice about what will happen to them.

It would be interesting to know what proportion of recommended care packages are turned down.

Appendix II Letter of response from chairperson of local research ethics committee

NORTHERN GENERAL
HOSPITAL N.H.S. TRUST

Herries Road,
Sheffield S5 7AU

Telephone
(0114) 243 4343

Facsimile
(0114) 256 0472

Minicom
(0114) 271 5896

TAG/SR/Gen Corres

5 August 1998

**NORTH SHEFFIELD RESEARCH
ETHICS COMMITTEE**

**Chairman: Dr T A Gray
Tel: (0114) 271 4309**

**Admin Sec: Sue Rose
Tel: (0114) 271 4011
Fax: (0114) 271 4771**

**e.mail:
Sue.Rose@dial.pipex.com**

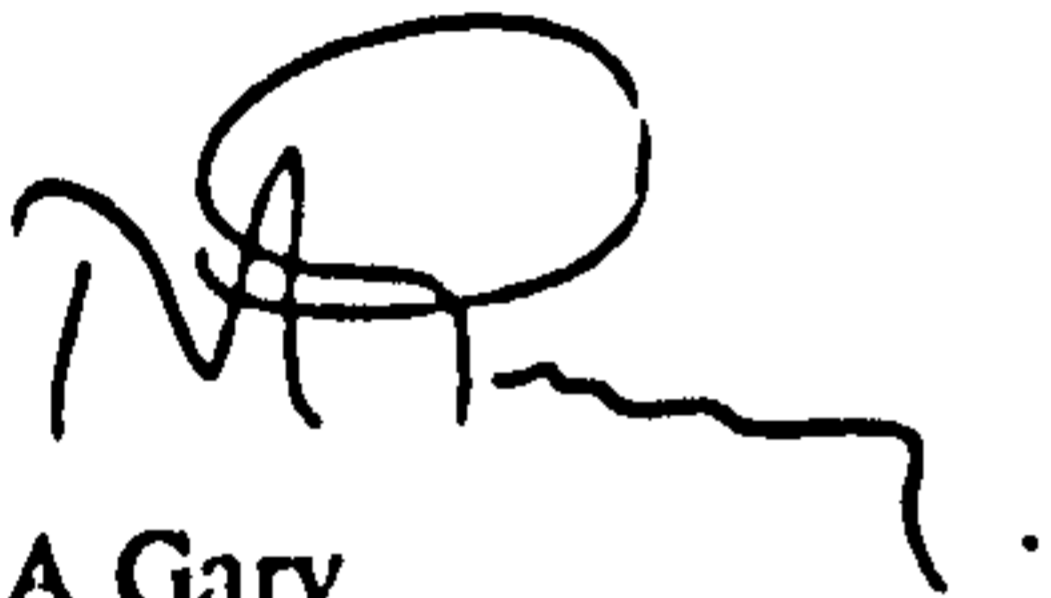
Ms Sue Davies
Lecturer in Nursing
School of Nursing and Midwifery
301 Glossop Road
SHEFFIELD

Dear Ms Davies

Re **Relatives experience of Nursing Home entry**

Following discussion with the Vice-Chairman of the LREC we feel that this project does not come under the terms of reference of a local Research Ethics Committee and, therefore, we do not need to see it. If you have any further queries about this please do not hesitate to contact me.

Yours sincerely



T A Gary
CHAIRMAN - RESEARCH ETHICS COMMITTEE
Consultant in Chemical Pathology

Appendix III Interview schedule used in Phase I

Relatives' Experiences of Nursing Home Entry

Interview Question Guidelines

Introduction

The interview will be informal and as much like a normal conversation as possible. I am particularly interested in your experiences and thoughts about the time surrounding the admission of your relative to a nursing home, and how things have been for you since then.

If you're not happy about answering any of the questions, please tell me. Also, if any of the events which I ask you about upset you and you want to stop, again, just let me know.

Everything you tell me will be strictly in confidence.

Start with biographical info. Age, family situation, work outside the home, relationship to the person who was admitted to a nursing home including dependency on participant for help, length of time since admission.

You were involved in helping your relative relocate into a nursing home. Could you think back to that time and tell me about the events that led up to the admission?

Anything that is or was important to you and might be helpful for me to know.

What prompted you to think about relocation to a nursing home?

Had you discussed the possibility of relocation with your relative beforehand or was this a decision you made on your own?

How did other people react, friends, family members?

What sort of information did you have to help you choose a home?

What sort of information would have been helpful?

Appendix III Interview schedule used in Phase I

Is there anything that nursing staff could have done to make the transition easier for you and your relative?

Did the staff assess your needs on admission?

Has your life changed by the experience of relocating your relative? If so, in what ways?

Are you happy with the care your relative receives?

What's good about it?

What's not good about it?

What sort of contact do you have with the staff?

What's it like visiting your relative?

Have you been able to maintain your relationship with your relative in the way that you wanted to?

Are there any other points you would like to add?

Thank you for your help. (Give information about Relatives' Association if appropriate)

Relatives' Experiences of Nursing Home Entry: an invitation to take part in a research project

I am a nurse researcher based at the School of Nursing and Midwifery at the University of Sheffield. I am carrying out a study to examine experiences of admission to a nursing home from the relatives' point of view. Nursing home entry of a close relative is experienced by an increasing number of people in this country. However, the majority of studies on nursing home admission have focused upon residents. I am interested in finding out from relatives who have experienced admission of a loved one to a nursing home, their perceptions, thought and feelings about this process.

Why am I approaching you?

The manager of the home to which your relative was admitted has identified you as someone who may be interested in taking part in the project. However, I have not been informed of your name and if you do not want to take part you need take no further action - I will not attempt to contact you again. If you would be willing to talk to me about your thoughts and feelings surrounding the relocation of your relative to a nursing home, please complete the slip attached and return it to me in the stamped addressed envelope provided. I will then contact you with more information before you make a final decision.

What is the research for?

When you tell me about your experiences of your relative's admission to a nursing home, we can learn to understand and inform others who will have this experience in the future. Your experience and knowledge can then help us to try to influence the education of nurses in the attempt to make them more aware and more understanding of the relatives' situation when a relative is admitted to a nursing home.

What will your involvement be?

If you agree to participate in the research, I will arrange to meet with you, at a time and place of your choosing, to talk with you for about an hour. I would like to tape-record our conversation to make sure that I have a full account of our

Appendix IV Information sheet about the study sent to Phase I participants

discussion. However, if you feel uncomfortable about the use of the tape-recorder just let me know and I will be able to take notes as we speak.

What will be done with the information you give me?

I will use your account of your experiences to prepare a written description. You will have the opportunity to read and comment upon this description in order to make sure that I have interpreted what you have said correctly. However, everything you tell me will be protected as confidential and you will not be identified personally in any reports arising from the study. From a number of these descriptions of relatives' experiences I will be able to make recommendations to nurses working in nursing homes and to those responsible for their training and education.

I hope that you will be interested in taking part in this important project. Thank you for taking the time to read this information letter.

Sue Davies
Lecturer in Nursing

Appendix V Outline of interview topics sent to Phase I participants

Relatives' Experiences of Nursing Home Entry

Interview Question Guidelines

The interview will be informal and as much like a normal conversation as possible. I am particularly interested in your experiences and thoughts about the time surrounding the admission of your relative to a nursing home, and how things have been for you since then. The sort of questions I will ask you might be:

You were involved in helping your relative relocate into a nursing home. Could you think back to that time and tell me about the experience?

What prompted you to think about relocation to a nursing home?

Had you discussed the possibility of relocation with your relative beforehand or was this a decision you made on your own?

What sort of information did you have to help you choose a home?

Has your life changed by the experience of relocating your relative?

Were you able to maintain your relationship with your relative in the way that you wanted to?

Is there anything that nursing staff could have done to make the transition easier for you and your relative?

Everything you tell me will be strictly in confidence.

Appendix VI Consent form for participants in Phase I

RELATIVES EXPERIENCES OF NURSING HOME ADMISSION

A Research Project undertaken by the Department of Gerontological and Continuing Care Nursing, University of Sheffield

CONSENT FORM

I,

.....

of.....

.....

.....

consent to take part in a research study entitled 'Relatives Experiences of Nursing Home Admission. The research and my involvement in it has been explained to me in writing and verbally. I understand that I will be encouraged to tell the researcher, Sue Davies, about my perceptions in relation to my relative's admission and relocation into a nursing home.

I understand that:

- after I sign this consent form I will be talking with the researcher for about an hour;
- a tape recorder will be used to get a full account of the conversation, or if I prefer, notes can be taken;
- if I wish, I will receive a copy of the researcher's summary of our conversation
- I can clarify and misperceptions I find of what I said, or meant to say, in the researcher's document, either by phone or in another meeting if I prefer;

I acknowledge that:

- I am over 18 years of age;
- the aims, methods, anticipated benefits and possible hazards of the research have been explained to me;
- I voluntarily and freely give my consent to participate in the research;
- I understand that the findings of the study will only be used for research purposes and may be reported in professional and scientific journals;

Appendix VI Consent form for participants in Phase I

- I understand that I am free to withdraw my consent to participate at any time, in which event my participation will cease immediately and any information obtained from me to that point will be destroyed if requested by me.
- I understand that my identify, and the identify of the persons, places and events about which I speak will be protected by the use of code names.

Signed

Participant Date

Signed

Researcher Date

Appendix VII Examples of interview summaries returned to participants

Relatives Experiences of Nursing Home Entry Study

Interview No 23

15/1/99

Mrs J. told me about the events leading up to her husband's admission to a nursing home in 1998. He had been retired about fifteen years when they both noticed a tremor in his hand. His GP was unconcerned and prescribed tranquillisers, suggesting it was 'nerves'. Over the summer period they saw a number of locum doctors who all said it was a nerve problem. However, when their own GP returned, she agreed to refer Mr J. to the hospital for tests. He was then diagnosed with Parkinson's disease. The consultant started him on some medication but he immediately began to have hallucinations.

One night he got up, and he's wandering down this corridor, and shouting and saying he didn't know where he was, and then I got up and put him to bed. And then the next morning, he said ooh it was funny last night, I got lost and somebody put me to bed, kind of thing. He didn't know it was me.

Mrs J. began to suspect that her husband might be developing some kind of dementia but when they went to the hospital they always seemed to be seen by a different doctor, who simply increased the dose of the medication. Mr J. had agreed to take part in some research trials and one of these trials involved going down to London for a scan. Although this didn't reveal very much, there was a slight grey area and Mrs J. asked if this could be an indication of dementia, but was told no. However, Mr J. was gradually getting so that he couldn't remember and Mrs J. was particularly concerned that he was still driving. Eventually, they were seen by a doctor who seemed more interested. He suggested that Mr J. should stop the medication completely and when their daughter questioned this he said 'Well you don't want him to be a zombie do you?' However, Mr J's condition then deteriorated even more.

Well then, he got a bit aggressive towards me. We decided to sleep in the back bedroom, because it was two single beds, and he was up and down all the time, he couldn't stay in bed more than ten minutes, he was wandering round and I had to get up. And he really got, once I was trying to help him and he pushed me away, you know, shouting. And I sent for the doctor and she gave him some medication to calm him down, but it didn't seem to make him any better.

In May 1997, the doctors decided to admit Mr J. to Hospital A. for observation. They tried him on a new drug but this just made him very drowsy. He was taken off this drug but remained very confused. Eventually, the doctors decided they could do no more for him and sent him home.

And he was home about two weeks, and well then one day he got up, at about half past five in the morning, and I was asking him to come back to bed. And he wouldn't at first. He could hardly walk. And so I tried to get him back into bed and he kind of

Appendix VII Examples of interview summaries returned to participants

slipped. And I couldn't get him up off the floor. So I didn't know what to do, so I rang the police you see. And they came and got him into bed, and said get in touch with your doctor, which I did. And again she tried to get him to be on an even keel. But he didn't show any improvement. He was getting very aggressive again. So they fetched him back into hospital.

It was decided that Mr J. ought to be assessed to see what help Mrs J needed at home. He was transferred to Hospital B. but both Mr and Mrs J. were very unhappy with the care he received there. Attempts to discuss his care with the medical staff were often unsuccessful and on one occasion, Mrs J's daughter took a day off work to accompany her mother to see the doctor to be told that the appointment had been cancelled. Eventually, Mr J's condition deteriorated to the extent that he had to be readmitted to Hospital A

And when we went, they said they'd ring me up when they'd got the tests, and when they rang up they said he's not well at all. If you'd like to come down and see him. And we went down and they said you can stay all night, because it doesn't seem as if he'll last the night. So we went down, I think my daughter had heard this before which is why she was coming, and we stayed all night. And they kept turning him every two hours. And he pulled through that. And they took him up to the ward, the same ward and this was the third time, so all the nurses knew him there. And they gradually pulled him round, kind of thing. But they said, he'd got bed sores and all sorts, but he hadn't been looked after properly at Hospital B. And he'd been neglected, and they said that.

Mr J. gradually became stronger but remained heavily dependent on nursing care. It was at this stage that the social worker suggested that he would need nursing home care. Mrs J. immediately thought of a home which had recently opened at the bottom of their road.

Well, the funny thing about it was, in '95, well it's been open about two years. We often used to go for walks around there, and we were passing the bottom blocks when it was kind of open for viewing. So we went in and, we'd not been in nursing homes, and it was like a hotel, it was marvellous. It was absolutely terrific. And in fact they'd even got the same wallpaper as we've got down the corridor and in the bedroom. And so that weekend when the three daughters rang, I said you don't need to worry about us when we're old.

Mrs J's main concern was whether the nursing home would accept Mr J as a resident. She visited the home with each of her three daughters, and all were very impressed with what they saw. However, they thought it was important to look around in order to make the right decision and looked at several other homes. One home was an old house which had been converted and they didn't feel it was so suitable. At another home, they were unimpressed by the attitude

Appendix VII Examples of interview summaries returned to participants

of the person who showed them around. One of the main advantages of Nursing Home A was its proximity. Mrs J's social worker arranged for the matron at nursing Home A to visit Mr J. in hospital to assess him and she felt that they could meet his needs, so he moved in in May 1998. Mrs J. feels that the staff take very good care of her husband but he seems to have lost interest in most things. She visits him every afternoon.

Well he can't stand or anything - his muscles have wasted. He couldn't feed himself, although he sometimes tries, although that's getting a bit few and far between. He used to kind of pick things up. Because if I take him grapes down, I put them there, sometimes he used to take them, he doesn't now, I have to pick them. He's no interest in things. Because he made all, lots of the furniture, he painted all these. So he's lost all that.

Mr J is now unable to hold a conversation and he is often very tired. Sometimes he sleeps throughout Mrs J's visit. He has a catheter because of his incontinence and this results in frequent bladder infections requiring antibiotics. The staff have told her that he is often brighter in the mornings but she prefers to visit in the afternoon because the staff are so busy in the mornings.

Mrs J feels comfortable with the decision for her husband to move into the home and thinks this is because he deteriorated over a long period of time and so she gradually got used to the idea that she would not always be able to meet his needs at home. In some ways Mr J. no longer seems like the same person she has shared her life with. Her daughters have been very supportive and she tries to keep cheerful for them. They even come to her at Christmas so that she doesn't miss visiting her husband.

Mrs J. feels that the staff at Nursing Home A make a real effort with her husband. The home is very clean and quiet and there are no unpleasant smells. Mrs J. feels particularly fortunate that they were able to secure full funding for her husband's placement with the help of their social worker. This took about a month to sort out, but even without this help they would have gone ahead with the placement:

...we'd have done it anyway. My daughter said don't worry because they're in quite good jobs. They said we can afford it, we'll help you and dad. They were worried that I'd say that I would have him at home. Because you see I thought round it, some people insist, even if you have people coming in to do things for you, it wouldn't be the same. I mean if they come in for breakfast, he might want to get up a couple of hours earlier or something. Whereas there it's all taken out of my hands.

The activities provided within the home are an additional bonus:

They have all sorts of things in the lounge, entertainment's and things. He goes in, but we visit in there sometimes. One or two

Appendix VII Examples of interview summaries returned to participants

of them have said oh we had an Irish night, a Scotch night, well he was tapping his feet to it, but I don't know that he knows what's really happening.

Mr J has his own en suite room with a television. His family took him in a radio and the staff sometimes put this on for him. Mrs J. normally visits in the afternoon and stays with her husband during afternoon tea. She feels it is important that she visits every day to provide some continuity for her husband. Mr and Mrs J. have been married for nearly fifty years and have had a happy life together. They have rarely been ill so the onset of Mr J's illness came as quite a shock. However, Mrs J. feels fortunate that they had fifteen years of retirement together.

He's a different person now from what he was before. So I go down and sit with him, still love him, it's not that I don't, but he's a different attitude if you know what I mean. I'm a bit tied that I go down there every day but I don't mind, it's a focus for my day. So it's not been as bad for me I don't think, as it would be for some people.

Mr J. has a special nurse and a special care worker who seem to work at different times. However, Mrs J. seems to have most contact with D, one of the male carers, because he shares many of the same interests as her husband. The staff change around quite frequently within the home but she does feel that they have made an effort to get to know Mr J. In particular, one of the managers asked if Mrs J could take in some of the woodcraft which Mr J. had made before he became ill:

He says I wonder if you could bring a few of the things down that he's made, because they were having a meeting with some of the carers and nurses about Parkinson's. And he thought this would show how Peter was before he was ill. Because they just know him as sitting there, kind of thing. So when J came that weekend we took quite a few things down that he'd made.

Mr J. doesn't see much of any other relatives when she visits her husband as she prefers to stay in his room with him. However, the staff have made some attempts to introduce her to relatives in a similar position. Mrs J described why one of the carers was particularly good:

Well she was always cheerful and would come and talk to you, when you went. And kind of, talked to Peter while you were there. You know and pull his legs and hug him, well they all do. In fact lots of the younger ones say, oh come on sexy Peter, and that, and laugh with him.

Mrs J could only think of one carer whose approach she has been less than happy with and this is because she doesn't share information about Mr J. so readily as the other staff, for example what he has eaten for dinner.

Appendix VII Examples of interview summaries returned to participants

Overall, Mrs J has been very happy with the care at Nursing Home A. She clearly remembers the day her husband moved in:

...they told me that they'd ring me up from (Hospital B) when he was moving, if I wanted to go down, which they did. And then I rang them up and said he's on his way. So I went straight down, but he hadn't arrived, but they took me to his room – lovely tray with flowers on and a rose in a vase, cup of tea and that. They were really nice. And said do you want to come and talk to us at the nurses' station, or do you want to stay in the room and wait for him. And I said oh I'll stay here. And I had a cup of tea and some biscuits. And then I suddenly heard and they were wheeling him down the corridor, and he seemed quite pleased.

One of the male carers, D., has been particularly kind and offered to help Mrs J. to take her husband home for an afternoon after his normal shift had finished. Mrs J. found this particularly helpful, because Mr J. did not seem to be aware of his surroundings during the visit and she realised that he would be no better off at home.

But another thing I miss is, if somebody tells me something about somebody we know, or I see something on telly where we've been, I think I must tell Peter about that. And then I realise, no I can't, and he doesn't know what I'm talking about, he doesn't remember any of it.

Although Mrs J. visits every day, she doesn't encourage other friends and relatives to visit as she knows that her husband would not want them to see him as he is now. She doesn't think he would know that they were there and she would prefer them to remember him as he was.

Mrs J. now takes each day as it comes. She has been told by her husband's GP that he has defied the doctors' expectations in that he wasn't expected to survive beyond six months when he was first hospitalised.

I can't think that, as things are, he couldn't be better really because with that being so handy and it being so nice, it's the best place for him and it's the best place for me.

Visiting her husband every day is very important to Mrs J.

Well I don't suppose he knows much about it, but I think they're looking after him so well, it's the least I can do to go and see him. I mean it's a kind of focus. If I didn't see him I'd be wondering is he all right, and not neglecting him. I know they wouldn't do. But I suppose it's for my guilty conscience in a way, although I still didn't really feel guilty about it, but you think it's the least you can do when they're doing all this for him. When you've been together all these years, the least you can do is to go and see them.

Appendix VII Examples of interview summaries returned to participants

Relatives Experiences of Nursing Home Entry Study

Relative Interview No. 16

14/12/98

Mr L. spoke about the events leading up to his mother's admission to a nursing home in June 1998. For the previous eleven years, Mrs L had been living in London and Mr. L visited her regularly. Mrs L. visited her son in Sheffield for Christmas (1997) but was unwell and stayed on throughout January, February and March. Mrs L's health deteriorated and it was quite traumatic for Mr. L trying to maintain a demanding job in addition to caring for her. As a single man, he found himself shouldering most of the responsibility for his mother's care. During this period she was also diagnosed with breast cancer.

It's not as though I could just delegate it to somebody else, you know and didn't have a wife at home that could take that burden off, off you know. So I got into a little bit of hot water in terms of the amount of time I was spending with mum. Which really forced me to say to mum, you know we've got to look at the home. But in the end I think you both come to terms with it.

In March 1998 Mr L. had to go to Norway on business and encouraged his mother to consider moving into a nursing home for a few days.

...although she'd always kept saying to me please don't put me in a home, promise me, in the end I said why don't you just go into (Nursing Home) for a couple of days so that I'm not worried about you at home and see if you like it. And I'd been in and seen S, the general manager as it was then at (Nursing Home). And she welcomed mum. Mum liked her very much and she went in. And that side of it all went fairly easy.

However, arranging funding for the placement has proved extremely complicated and has still not been resolved. Although Mrs L. has a small occupational pension in addition to her state pension, these were insufficient to cover the fees for the home. The difficulty arose because the authority where Mrs L. lived declined to fund a placement in Sheffield. However, Sheffield City Council also denied responsibility. Mr L. would have been happy to fund the difference himself if this was tax deductible; however, this appears not to be the case. The local authority in London have also argued that Mrs L. needs residential rather than nursing care, the allowance for which is much lower. However, Mr L. is convinced that she should qualify for nursing care. Staff at the home have fortunately been very understanding about payment.

Mr L. chose Nursing Home A because it was close to where he lives. It was also more like a hotel than a nursing home. Mrs L. is very particular about hygiene and some of the homes Mr L. visited had a strong smell of urine. (Nursing Home) is also very quiet whereas other homes seemed to have bells and buzzers constantly ringing. Mrs L. has very good hearing and has chosen a corner room away from the hub-bub of the home. Nursing home A is purpose

Appendix VII Examples of interview summaries returned to participants

built, but with hindsight, Mr L. might have chosen a home with a wider choice of sitting areas as there is only one large lounge. Because of this Mrs L. generally chooses to stay in her room.

Although the facilities at Nursing home A are adequate, Mr L. has been less happy with some aspects of the nursing care. In particular he has had concerns about whether his mother always receives the appropriate medication. In October 1998, Mrs L's condition deteriorated and staff at the home suggested that she was terminally ill. They were keen to start her on diamorphine to control her pain but this caused her to become very confused and Mr L. began to question this aspect of her care. Mrs L. recovered from this episode but the family found it very upsetting.

And in the end, it really seemed that this combination of drugs was wrong. And one of the nurses who's very nice in (Nursing Home A), said to me, M, why don't we have a word with the Macmillan nurses. So we decided to do that, got them in. Oh, she said, it's totally the wrong drugs for this condition so we put her on a new drug. Something to quieten her down because she was very frightened.

Mr L. now finds it difficult to trust the staff completely and feels he needs to check aspects of his mother's care. He visits her every morning and evening and helps her to get ready for bed.

I didn't put her in the home to forget about her. And I find it hard to go away and leave her, you know. She's very sweet to us and she's always been good fun, and I don't want to, I couldn't just, I mean it really upsets me some of the ways some of the old people are left. If I didn't talk to them sometimes, I don't think they'd have anybody talk to them.

Mr L. feels that some of the care assistants are better at their job than others. In particular, he feels that many of the agency staff don't really understand the needs of the residents. While he feels staffing levels are generally adequate, there are often problems at night.

Sometimes they have awful nights, and I've been in there because mum will phone me in the middle of the night, she gets frightened, and if she doesn't trust the nurse who's on sometimes even she wets the bed. She won't tell the nurse. She gets embarrassed. So she'll ring, and so I go in at four in the morning, or something like that. And you find that they do have awful nights.

The home recently had a change of manager and a change of matron and Mr L. feels that the current senior staff are possibly not so in touch with the needs of residents. Mr L. tries to work with the staff, but does feel the need to monitor his mother's care quite closely. He feels concerned for other residents within the home who don't have relatives to advocate on their behalf and often finds

Appendix VII Examples of interview summaries returned to participants

himself carrying out small tasks for them. The care assistants at the home vary in their ability to do the job well, although some are very capable.

N knows everybody's name, you know. If he gets told about things he remembers. There's another lady who's ninety seven - it's just the way he handles her, the way he talks to mum, you know, 'Hello Ellen'. It's, when you hear his voice, it's because he's pleased to see her. There's another chap downstairs that, to look at him you think he's the most unlikely person to be a carer, but you know, if he sees mum - I brought mum back last night after we'd been out for the afternoon and he was so pleased to see her - 'Hello Ellen you've not had your kiss today', you know, and he means it.

On the other hand, some of the qualified staff are quite 'laid back' in their approach. One older nurse in particular seemed very reluctant to change Mrs L's dressings even though they were leaking and obviously needed to be changed. It took some time for the staff to hit upon the appropriate dressings for Mrs L. and this has caused Mr L. to question the expertise of some of the qualified staff.

Mr L. is still very involved in his mother's personal care as this is what she prefers. His company have now accepted that he needs to spend more time with his mother, which he feels is entirely appropriate since he has given the company very good service for more than thirty-five years. Mr L. feels that his mother still has a good quality of life, particularly now that they seem to have hit on the right combination of drugs to control her pain. The breast cancer does not appear to cause her any particular problems and her doctors have decided not to operate to remove the breast lump. She is taking Tamoxifen to control the disease. In particular, when Mrs L. first moved into the home, it seemed as if she had a new lease of life and she spent a very happy Summer, going out on trips and making friends within the home. Following her deterioration in the Autumn she is now more frail but still able to enjoy life. Mr L. tries to stick to a routine when he visits.

You see we have a routine in the evenings. She likes the routines. So I get there about say seven thirty, eight o'clock. So we immediately get ready for bed. I prepare the bed for the evening and I wash her, I say 'Do you want a wash?' do you want a bath?'. So we decide what we're going to do, it's a bit like coming home, you know. What things we're going to wear the next day, put them in the wardrobe and that sort of thing. And, then we have a wash, it takes me, you know it takes a good half hour to wash her, you can't rush it that much. So, I just wash and we chat, put the television on. Sometimes we phone people, you know, we maybe phone my sister or she'll phone a friend. If I prompt her to do it, she'll do it. But she won't pick the phone up now. She gets very confused about what medicines she's had. She keeps saying to me 'Have I had this tablet or that'. So I usually check that out. Some evenings she goes in her

Appendix VII Examples of interview summaries returned to participants

wheelchair, goes to her friend's, and sits and has the evening drink with her for an hour.

With hindsight, Mr L. realises that he was very stressed when he was trying to care for his mother at home and thinks he should have insisted on having more help. The main reason that he didn't employ agency staff at this time was that his mother preferred him to provide her care, but on reflection he thinks he should have been firmer with her.

Mr L. has always been close to his mother. He remembers her as being a lot of fun when they were younger. Since her second husband died fifteen years ago they have spent a good deal of time together. Mrs L's other three children are still in regular contact and visit from time to time, although they all have other family commitments. However, Mr L. doesn't feel that his mother is a burden.

Not really a burden at all I would say. Just, it stops you doing, I mean this Christmas I can't do what I want to do, and she keeps saying to me 'You won't go away and leave me will you?', you know. So, it's a little bit, I just feel it's a period, I feel it won't go on for ever.

I don't want to sound as though I'm doing it out of a sense of duty, because I do it out of my own love I have for her. The giving, if it's giving is natural, it's not something I feel forced to do. And in return, if she smiles at me that's enough, you know. Like yesterday morning, she's not a cuddly kissy person you know, never has been, but after I got her ready she said 'Can I give you a kiss?', so that to me was everything.

Mr L. feels that the staff are quite good at responding to his concerns and requests.

I just go and see them and I try to be very polite. I don't want to talk down to anybody. I just say my opinion is that mum needs this or this attending to, they know with me, and invariably when I go back it's done. I don't really have to say, I just say 'I don't want you to drop everything', because maybe they are with somebody else or they are on their way to doing something. I just say 'Would you kindly look at this'. Like this morning I said 'It's two days now since her legs were done': there was a very nice nurse on...So I just said to Julie would you put, 'Yes of course I will'. And I know it will be done.

Mr L. continues to have concerns about the way in which medications are administered within the home. A recent drug error where a resident was given another resident's medication has led to a number of changes, but Mr L. feels that residents' records could be better organised. Also, drugs are not always ordered in good time.

In terms of support, Mr L. feels that his GP could perhaps have been more

Appendix VII Examples of interview summaries returned to participants

helpful. The GP advised against admission to Nursing Home A as he did not rate the care highly. Mr L. feels that this was largely the result of a personality clash between the GP and the manager of the home and feels that his GP should have been able to offer a more objective view.

Mr L. has found some of the publications produced by Help the Aged very useful and feels that older people should have a higher profile, for example in charitable efforts. He also draws strength from his faith, and wishes that his mother had a stronger faith to support her.

Returning to financial matters, Mr L reiterated how complicated the system appears to be, and how, with constant legislation, the situation is continually changing.

I think people need, I think they need a one stop service, you know -I've got an elderly relative, this is the situation, this is her income, this is what we could afford, or what we couldn't afford, what do we do, where do we go from here? You're shunted from this department to the local authority, to another department.

He has also found some of the enquiries into his mother's financial status quite intrusive and feels that the onus is on him to demonstrate that she is unable to meet the fees from her own income.

The decision to place his mother in the nursing home has not been an easy one for Mr L.

...the worst words she ever said to me, you know they often ring in my ears, 'You won't put me in a home'. Because when we were naughty when we were children, she'd say if you don't behave I'll put you in a home. And it sort of rings back as though you're sort of doing the same thing in getting your revenge, you know.

One of the most distressing incidents for Mr L. was when staff at the home told him that they didn't think his mother would live much longer.

I think when they saw how much it upset me, they rallied. And I did notice that a lot. But they realised that, when he said she would pass, in his words I expected her to die within the week, that really upset me. It didn't kind of hit me there and then in the room, but it got me over the next couple of weeks. And of course I was expecting it all the time.

Although there is no regular formal review of his mother's care, Mr L. can ask to meet with the staff at any time.

It's not that structured. I mean, you can ask to see them any time, and if I say I want a meeting, they always respond. I think

Appendix VII Examples of interview summaries returned to participants

they rely on, if you feel that everything is okay, and you're happy then we leave it alone.

Mr L. has regular contact with a number of the other residents and enjoys speaking with them when he visits. He has also got to know some of the other relatives through attendance at social events. Although there is no formal relatives' committee, relatives and friends are welcome to attend meetings of the residents' committee where one of the main complaints is food.

Finally, Mr L. described his current role in his mother's life.

I'm there for her, that's the main thing . She knows that, I said any time, day or night, if you're really upset, you just pick up that telephone, you only have to press that button, because it's programmed in, and I'll be there, you know. So what I must do, to be clear in my own mind and conscience and everything, is to be there for her, and I really hope nothing ever happens when I was a long way away....So I think to sum it up, just to support her, to make her as comfortable as I can, and pain free, for however long it takes, you know. That's really it.

Appendix VIII Reflective account of the use of QSR NUD*IST to assist with analysis of interview transcripts

Personal reflections on the use of QSR NUD*IST

QSR NUD*IST (Non-numerical, Unstructured, Data: Indexing, Searching and Theorising) is a computer package for the analysis of qualitative data. Essentially, it is a methodological 'tool-kit' which allows a researcher to 'see the story in complicated data and find out what's going on' and 'do the data justice, not just summarising it but really exploring' (Gahan and Hannibal 1998). NUD*IST works with textual and non-textual documents and facilitates the indexing of components of these documents. It is able to search for words and phrases very quickly and contains extensive features which support the construction of hierarchies of code categories. It also allows the researcher to compile 'short comments or 'memos' on the data and to link these either to text segments, codes or other memos. The authors claim that NUDIST supports the development of theory by enabling the retrieval of indexed text segments and related memos and through the construction of a hierarchically structured tree to order index categories (Buston 1997).

Recently, concerns have been expressed that the use of computer packages to assist in the analysis of qualitative data may be inconsistent with the assumptions underpinning the use of different qualitative research strategies, including constructivist inquiry (Coffey et al 1996, Seidel and Kelle 1995). These concerns stem from apprehension that the structured nature of the package will detract from the process of intellectual theorising.

However, Kelle argues that the most common use of these programmes is to assist with the basic tasks of data coding and retrieval (Kelle 1997). Since qualitative analysis programmes do not represent a different logic of textual data management, but rather an extension of code and retrieve facilities, they should pose no threat to the intellectual imagination. What remains unclear is whether these extended features can exceed the analytical possibilities offered by manual methods.

I found QSR NUDIST to be an invaluable tool in the practical task of coding and labelling data. In particular the processes of unitising and categorising data could be

Appendix VIII Reflective account of the use of QSR NUD*IST to assist with analysis of interview transcripts

thoroughly and rapidly accomplished (certainly more rapidly than via manual procedures). Lincoln and Guba (1985) highlight the tendency to label textual data as irrelevant because of the effort involved in coding and labelling them. This process is rendered so effortless with QSR NUD*IST that this particular danger is easily avoided. However, the opposing pitfall of coding everything simply because it is so easy to do so should also be avoided – otherwise the volume of ‘miscellaneous’ data (Erlandson et al 1993) is likely to be considerable.

A further advantage of NUD*IST relates to the ease of relocating units in their original context because effectively, they have never been separated from that context. Use of the ‘spread’ function immediately retrieves the text around a particular fragment and this can be extended until the full context is revealed.

The creators of NUD*IST themselves acknowledge the difficulty of theory construction in the absence of conceptual maps (Richards and Richards 1998). While working in the package I found it difficult to visualise how ‘branches’ of the hierarchical tree structure might relate to each other. I was forced to resort to printing out my coding structure at intervals (which, including sub-codes, often stretched to twenty pages or more), and exploring possible inter-linkages with pen and paper. However, it was then very simple to relocate and merge codes or ‘nodes’ in order to reflect the new structure. Certainly, this simplicity of coding, re-coding, merging and reattaching nodes encouraged a thorough exploration of the data. It was also possible to access all categories and codes for an individual interview at the press of a button enabling patterns of meaning to be traced for individual participants.

My conclusion based upon these experiences is that QSR NUD*IST is a useful accessory to assist in the analysis of qualitative data, but that it does not in itself provide a framework for analysis. However, used in conjunction with a specified and explicit analytical framework, then it is likely to result in a more thorough and rigorous analysis than if manual methods of coding were used.

Appendix IX Early categorisation of data: NUD*IST index roots

INDEX TREE ROOTS

CONTEXTUAL DATA

e.g. age of older person and relative, family structure

PRECIPITATING EVENTS

e.g. stroke, hospital admission, change in partner's condition

DECISION-MAKING

e.g. how many homes?, no ideal solution, wanting the best

CHARACTERISTICS OF THE HOME

e.g. brochures, exclusion criteria, food, laundry

ASSESSMENT

e.g. involving relatives, treating people as individuals, assessing need for therapy

DEMANDS ON THE RELATIVE

e.g. combining caring with family commitments, problems with transport, putting yourself second, wanting to be appreciative

DEMANDS ON THE STAFF

e.g. balancing the needs of all the residents, older person being demanding, poor pay, working to guidelines, staff shortages

EXPECTATIONS

e.g. community care as a right, care planning should be explicit, homes should have a grading system, partnership with staff

EXPERIENCES

e.g. being left to get on with it, inaccurate information, nursing staff applying pressure to find somewhere quickly, professionals being helpful

PERCEPTIONS

e.g. EMI home as the last resort, ward nurses not involved in relocation, its a business, residents are drugged

OLDER PERSON'S EMOTIONS

e.g. being resigned to it, happy in the home, not realising its final, feeling like a prisoner

RELATIONSHIP WITH THE OLDER PERSON

e.g. not talking about it beforehand, being too close, feeling resentful, breaking promises

Appendix IX Early categorisation of data: NUD*IST index roots

RELATIVE'S EMOTIONS

feeling guilty, feeling out of control, having no life of your own, staff weren't me

RELATIVE'S ROLE

e.g. filling the gaps, advocacy, bringing in something different, protecting the older person

STRATEGIES

e.g. accepting the inevitable, being the sort of person they would like, abiding by the rules, keeping on the right side of the staff, complaining, ultimatums

+ free nodes

Appendix X Examples of theoretical propositions emerging from the interview data

Examples of theoretical propositions generated during analysis of Phase I interviews in relation to the phase 'Making it better'.

'Making it better' Relatives see an important role for themselves in helping the older person to achieve the maximum quality of life within a compromise environment.

Maintaining continuity involves helping the resident to maintain their identity. This involves them in:

- ◆ making the staff aware of the older person's identity
- ◆ continuing to engage in familiar pastimes
- ◆ helping the older person to maintain contacts with family and friends
- ◆ helping them to take part in activities relevant to their religious faith
- ◆ reminding them of things that have happened in the past
- ◆ visiting old 'haunts' together

Relatives help to create a sense of community within the home and see an important role in this. They do this by:

- ◆ joining in with social events
- ◆ initiating social events
- ◆ spending time with other residents when they visit
- ◆ being aware of the culture and modifying their activities accordingly
- ◆ developing affection for other residents
- ◆ encouraging the older person to mix
- ◆ fund-raising for the home
- ◆ engaging in helping activities e.g. giving out hot drinks

Appendix X Examples of theoretical propositions emerging from the interview data

- ◆ listening to the needs of staff
- ◆ seeking feedback on events within the home
- ◆ bringing in things for the home
- ◆ treating it like home
- ◆ helping other residents
- ◆ seeking out other relatives and engaging them in conversation

Relatives see an important role in keeping an eye on the standard of care the older person receives. This involves:

- ◆ monitoring the older person
- ◆ seeking information from other residents and relatives
- ◆ visiting regularly
- ◆ seeking information from staff
- ◆ maintaining contact by telephone

Appendix XI : Characteristics of participants in Phase I interviews

Inter- view No.	Gender of participant	Age of participa nt	Relationship of person in care home to participant	Time since admission
1	female	45	Mother	5 years
2	female	54	Mother	2 years
3	female male	51 52	Mother in law Mother	2 months
4	female	63	Mother	5 years (mother now deceased)
5	female	38	Father	18 months
6	male	58	Aunt	2 years
7	female	47	Mother	5 years
8	female male	50 53	Mother Mother in law	1 year
9	female	52	Mother	10 months
10	female male	60 68	Father Father in law	2 years
11	Female male	60	Mother and father	1 year
12	Male female	53	Mother and father	1 year
13	female	62	Mother	13 months
14	male	81	Husband	8 months
15	Male	78	Husband	
16	Male	48	Son	8 months
17	Male	49	Son	3 weeks
18	Female	60	Daughter Son-in-law	7 months
19	Male	82	Spouse	5 months
20	Female	83	Daughter	2 years
21	Female	84	Niece	4 months
22	Female	84	Daughter	8 months
23	Female	79	Wife	8 months
24	Male Female	80 35	Husband Daughter in law	18 months
25	Female	60	Daughter	18 months
26	Male	45	Son	1 year (recently deceased)
27	Female	52	Daughter	20 months
28	Female	62	Niece	13 months
29	Female	43	Daughter	2 years (recently deceased)
30	Female	56	Daughter	6 months
31	Male	80	Husband	15 months
32	Male	81	Husband	4 months
33	Male	84	Husband	8 months
34	Female	82	Wife	14 months
35	Female	79	Wife	7 months
36	Female	76	Wife	1 year
37	Female	50	Daughter	6 months

**WANTING WHAT'S BEST FOR THEM: RELATIVES
EXPERIENCES OF NURSING HOME ENTRY**

Sue Davies
Lecturer in Nursing



SUMMARY OF KEY POINTS FROM THE STUDY

1. Moving into a residential or nursing home is a major life event with important repercussions for older people and their family members.
2. Relatives' experiences of helping an older person to move into a care home are extremely variable. However, the extent to which they feel supported and are able to feel in control of the process are important factors in achieving a positive experience.
3. The single, most important factor guiding and motivating relatives throughout the period of the move is wanting what is best for the older person. This needs to be balanced with a host of other factors, including the views of other family members, the views of professionals and their own ability to continue to care.
4. The most positive experiences appear to result when the decision to move into a care home and the choice of home can take place without pressure of time or resources.
5. Relatives and older people planning a move often lack up to date and relevant information to help them to make choices.
6. The financial aspects of moving into a care home are often complex, difficult to understand and organise, and can put severe strain on a family's finances.
7. The most appropriate care home environment is one, which reflects a homely, domestic setting as far as possible. Smaller homes, or homes which are divided into group living units enable relatives to get to know staff and become more involved.
8. The day of the move into the home can be a particularly difficult time and practical arrangements, such as appropriate transport, a warm welcome on arrival and ensuring that the older person's room is prepared can make a traumatic experience easier to deal with.
9. The process of assessment of the older person's needs on admission to the home frequently fails to draw upon relatives' expertise and knowledge. Few relatives felt that their own needs were assessed at this time, although care home staff were generally supportive.

Appendix XII Summary of interview findings posted to Phase I participants

10. Relatives attach a great deal of importance to their continued involvement in the life of the person following the move. They see their role as having three main components:
- ◆ helping the older person to maintain their sense of identity through the continuation of loving family relationships and through helping the staff to get to know them as an individual
 - ◆ creating a sense of community within the care home, by interacting with other residents, relatives and staff, taking part in social events and generally providing a link with the outside world
 - ◆ ensuring best care, by monitoring the care received, providing feedback to staff and filling any gaps.
10. Most relatives have a clear understanding of the standard of care they would like their relative to receive but for some relatives, the reality of care frequently fails to meet these expectations.
11. When care fails to meet the standards which relatives expect, they may use a range of strategies to try to improve things, including showing staff how to deliver care, making requests and making formal complaints. However, a significant proportion of relatives appear to feel that they have no option but to 'keep quiet' in order to avoid upsetting staff and possibly further jeopardising their relative's care.
12. The way in which care home staff respond to relatives' attempts to achieve the best possible care result in one of four possible types of relationship with staff:
- ◆ Partnership care - 'Working together'
 - ◆ Substitutive care - 'Doing it yourself'
 - ◆ Submissive care - 'Putting up with it'
 - ◆ Conflict in care - 'Battling it out'

The final three types of relationship leave relatives feeling frustrated and angry or resigned to their situation. Where partnership care can be achieved, this has positive benefits for relatives, for residents and for staff. The final stage in family caregiving can then be perceived as a time of enrichment for all involved.





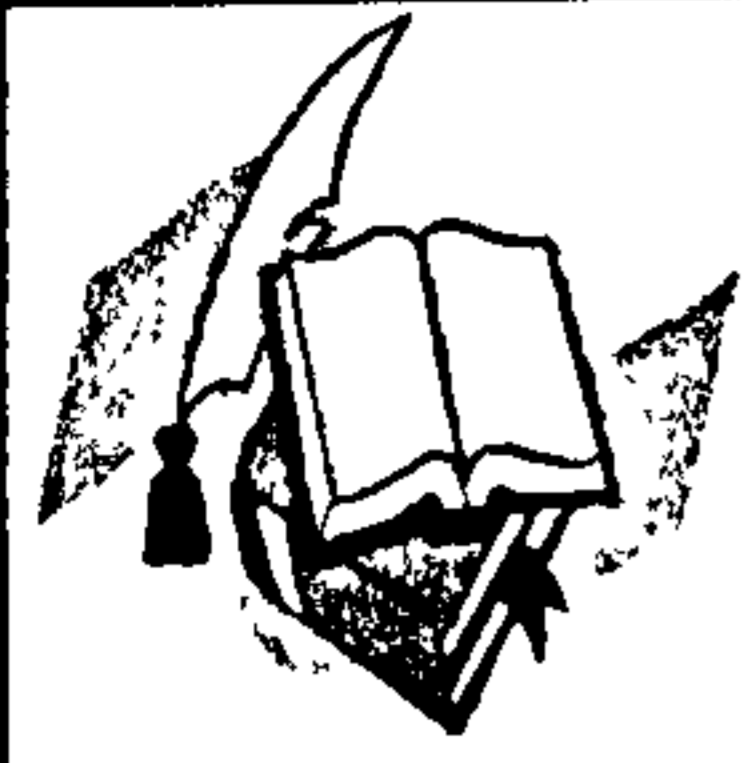
**(NURSING HOME A)
PRACTICE DEVELOPMENT PROJECT**

As you know, in September 1998, I began to spend time at (Nursing Home A), working alongside the staff and gathering impressions about nursing home life to inform my research. We agreed that I would feed back my findings in order to suggest areas for practice development. I have now spent a total of fifteen days over a six month period, talking with residents, relatives and staff and joining in with the day-to-day work in the home. This has given me some useful insights into different aspects of life at (Nursing Home A). This brief report explores some of these issues in detail and, I hope, will provide the starting point for thinking about things you would like to change.

Issues raised by residents and relatives and issues raised by staff are considered separately, although as you will see, there is obvious overlap.

STAFF ISSUES

The overwhelming finding from the interviews with staff was how committed they are to the residents at (Nursing Home A) and how much they enjoy their work with older people. Many mentioned the sense of achievement which they feel at the end of a shift and how they are able to take pride in their work. Staff enjoy working as part of a team but this can be difficult when short-staffed. Most members of staff feel that personal care for residents, in relation to meeting hygiene needs and looking after personal clothing for example, is of a high standard. However, a number of common concerns were raised and these are detailed below with examples. Nearly all the staff interviewed felt that there were insufficient carers on each shift to be able to provide the sort of care they would like. However, on further questioning it became apparent that this was often due to staff sickness leaving a shortfall rather than systematic under-staffing. It also emerged that there were some changes which might save staff time and hence free up time for other activities.



Lack of stimulation for residents

Nearly all staff suggested that having more staff on each shift would mean that they could spend more time with residents. Having time to sit and talk with residents and finding out more about them was felt to be of vital importance to maintaining their quality of life.

Its important to make them laugh, have good times with them. Its nice to sit down with them when you can but when you haven't got time you think 'what must they be feeling like, just sat there watching telly all day with no one to talk to , just four walls.

Some felt that structured activities are directed towards a minority of more able residents and that the majority of residents have very little to occupy them.

There should be more activities available, something they can do. Perhaps some of them would like to knit. There should be something they can do like ask for it or just get up and get it. Because they're that bored some of them it must finish them off, they're just looking at the walls.

We need to think what would I like? The .activities programme seems to focus on the residents downstairs.

Innovative suggestions included a pet visiting scheme and a fish tank in each sitting area! Opportunities to listen to music rather than watching television were also suggested.

Many staff members mentioned the importance of being able to develop special relationships with individual residents. The ability to know a resident's day-to-day routine and their individual likes and dislikes which develops from continuity of care-giving was mentioned repeatedly. This works both ways since staff also feel more appreciated when they are able to develop relationships with particular residents.



Information about residents

A majority of staff interviewed suggested that they would like more information about individual residents, particularly about their nursing needs, and about the conditions affecting them. Some staff felt that very little information is provided during the handover and that some qualified staff use medical terms and 'jargon' which they don't understand. Several members of staff suggested that the handover report at 07.15 should be to all staff as they sometimes find themselves providing care to residents without up to date information.

You have to find out about the residents as you go. I think it would be good if the qualified staff would sit you down and run through the care plans with you on a daily basis, to get to know what their needs are. But that's not being done.

Many care assistants also felt the need for more detailed biographical information about residents.

We need more information about what jobs they used to do when they were younger. It would be nice to have a little booklet or something to just show us what life they had. They were like us once.

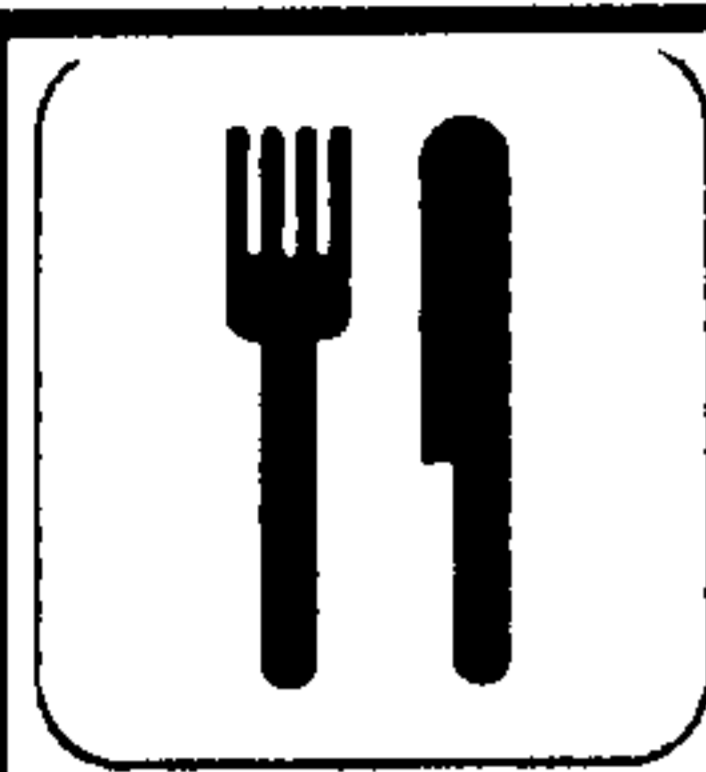
One or two care assistants felt that they could be involved in gathering this information and sharing it during report: however, others felt that they might lack the confidence to do this.



Equipment

Many staff members mentioned the lack of basic equipment and the poor condition of many items of equipment, particularly wheelchairs. Many wheelchairs have missing foot-plates and non-functioning brakes. The general ethos of lifting residents was criticised and some staff felt that they were putting themselves at risk by continuing to manually lift heavy residents. On the other hand, some staff members felt that staff were left sitting in wheelchairs for too long, particularly at meal-times and that residents should be helped to transfer to dining chairs in the dining room.

Several members of staff mentioned the need for more supplies around the home, particularly toiletries, and suggested these should be readily available in bathrooms. This would save time in running around to fetch essential items when helping residents to meet hygiene needs.



Routines

A number of people commented on the way in which the routine within the home seems to dominate the residents' day, particularly in relation to meal-times. Several members of staff mentioned the pressure which they feel to 'get the work done', particularly within the morning shift, when some of this work could easily be transferred to the afternoon. Meal-times were felt to be 'chaotic' and 'rushed', although this does vary from day to day.

The meals. Choice would help. Its nice to be asked. Some people do not know what they want but you could always sort that out. Meal times are chaotic but it helps when there are less residents. It comes down to who is doing this, who is doing that. You don't know who is doing what. How do you know who has had their dinner?



Respect for each other

About a third of the staff members interviewed mentioned concerns about the way in which some members of staff talk to residents and fail to treat them with respect. This related also to protecting residents' rights to dignity and privacy, for example always remembering to knock and wait for a reply (where appropriate) before entering a resident's room. Talking to residents while providing personal care was felt to be particularly important.

Say, when you're taking a resident to the toilet, you should tell them what you're doing even if you think they don't understand. Rather than hoicking them out of a chair without a word being said. We don't know what's going through their mind and I think its just good manners.

While generally relationships between members of staff were felt to be good, there was some criticism for the hierarchy of roles within the home. In

Appendix XIII Case report discussed with staff at Case Study Site 1: Nursing Home A

particular, the system of having different coloured belts for care assistants of different seniority was criticised on several occasions. Some care assistants felt that this failed to reflect the experience they had gained working in other homes.

Its not as if I've just come into the job and I don't know what I'm doing and I need to be supervised. I feel like sometimes I'm being watched more than others.

If you have two qualified staff on upstairs that's OK. it depends which qualified are on. If they're hands on its OK although the qualified staff could help us more. Since I've been here I've had a run-in with one of the qualifieds because they talked down to me and I didn't like it. If they want respect they've got to respect us as well. We know these residents better than they do. We're with them seven hours a day and if they're ill we can tell. We're not qualified but you know when they're not right don't you.

However, care assistants also recognised the pressures on qualified staff, particularly when there was only one nurse covering a shift.



Training opportunities

All staff welcome opportunities for in-service training although some people suggested that *'the best way to learn how to do the job is to get on and do it'* and that *'caring for older people is basically common sense'*. Some staff mentioned the induction programme which they had found particularly helpful. Others would welcome more clinical supervision from qualified staff and the opportunity to work alongside qualified staff more, particularly those undertaking NVQs. Suggestions for further training included:

- first aid
- coping with death and dying
- pressure area care
- continence care
- specific conditions such as Parkinson's disease and stroke

RESIDENT AND RELATIVE ISSUES A total of nine residents and four relatives were interviewed, mostly in a very unstructured way as it was found to be inappropriate to use a structured interview schedule. Residents were asked what they liked about living at (Nursing Home A) and about things which they would like to change. They were also asked to talk about a nurse or carer who had particularly helped them, although some found this difficult

to remember. The most useful information came from asking residents to describe their usual day and to say what effect moving in to a nursing home has had on their lives.

Although most residents said that they would prefer to be in their own homes, nearly all were happy to be living at (Nursing Home A) and felt that the staff are generally kind and helpful. Residents commented on the comfort and decor within the home and most liked their rooms. Most residents found it hard to think of something they would like to change but the following issues were identified by several residents.



Having to fit in with the routine

Like the staff, some residents felt that the routine within the home means that on occasions their individual needs are not met. For example, some mentioned the lack of choice over whether to have a wash or a bath and felt that there was really no choice about this.

You've got to have a bath whether you like it or not. They tell you in the morning whether you are having a bath or not.

For one resident, this lack of choice was most acutely felt in relation to where she was encouraged to sit in the dining room:

Well there's a table next to us and there's two women - ooh and they're terrible. they sit staring at us. Well they've put one of them on our table this morning and we weren't very pleased with that. Our names are meant to be on our table. There's five of us on our table and we're all comfortable. But she spoilt it this morning.

For several residents, one of the main things they miss about living in the home is not being able to have a cup of tea when they want one.

I've been in Hallamshire hospital a while since, but if you happened to say oh I can't go to sleep, they go round in the night and she'd say wait a minute, and she'd bring you a lovely mug of tea. But they won't do that here. I only asked once and she said 'I've my work to do, get to sleep'. Oh she was nasty. I've my work to do. I can't be getting you cups of tea.

Some female residents said that they would prefer female carers to perform personal care tasks whenever possible and felt this had never been discussed with them.



Activities and outings

A second theme to emerge from the interviews with residents was a wish for more activities to prevent boredom. Those residents who were taken on outings enjoyed themselves and wished that these could happen more often.

Time to 'chat' with staff was highly valued but happens less frequently than residents would like.

I don't get no company that's the point I'm on my own. I might as well be at home in my own bedroom. People don't take the time to talk. That's the trouble, I've nobody to talk to. I'm on my own so much and I like a bit of company. I've nobody at home. Nobody comes now to see me. Still I suppose they have other things to do.

Even when staff do not have the resources for formal activities and outings, just 'popping in' to check that residents are alright is appreciated.

I'd like someone to occasionally come in to see if theres anything I want doing. Even if its only a few minutes, say ten minutes or so just to sort things out a little bit. It doesn't need to be at a fixed time - anytime would be alright 'I'm always at home'.



Food

While some residents said that they were very happy with the food at (Nursing Home A), many were critical:

Sometimes the food is awful. They get a lot of parsnips - nobody eats them but they will insist on sending them

There's only one thing I don't like and its meals Mind you if they can find me an alternative they will do. I don't like the mashed potatoes, I don't like turnips. The greens all seem to be frozen and I love greens when they're firm.

I haven't been very happy with the food and it doesn't seem to be getting any better. If there were a bit of bacon and tomato

or boiled egg now and again, but not hard boiled. Its a long time since you had something like that.



Relationships with staff

While on the whole, residents and relatives perceive staff as cheerful, kind and friendly, some appear to take to heart perceived criticism from members of staff:

I don't use the commode very often at night - on average about twice. To me, I'm a little bit on the nervous side and there's one - she's always rushing me. The other night I said 'Oh for goodness sake go out a bit' because if they go out I can manage. Now some of them are very very good - they say Oh we'll just have a little walk and its all the difference. But this one - she burst out the other night, went straight to the sister and complained about me and the sister came in here and she thoroughly tore me a strip off which I thought wasn't very nice. I mean I pay my money to be looked after, not to be dictated to.

When things are not going to my liking, if somebody starts arguing with me, I have to say what I think. There's that many here that have lost their memories, they can't do it so I'm sort of odd one out. I can't stand being put on.

In the activity room, sister said 'its like a hell-hole in here' but she said it specifically to me - she singled me out.

For the majority of residents, all their interests are focused within the home, and it is quite possible that simple remarks may be taken out of proportion. Similarly, what may appear to be quite trivial incidents to staff can assume enormous significance for residents. One lady for example appeared anxious throughout the interview that she had lost some underwear and was extremely grateful and relieved when a member of the cleaning staff retrieved these for her.

Most residents spoke warmly of individual members of staff and obviously appreciate the special relationships they have with them.

(N) came to say goodnight to me because she wasn't going to see me for two days.

Appendix XIII Case report discussed with staff at Case Study Site 1: Nursing Home A

I'm very fond of N. She's slow but she's very thorough. Whatever you ask its done. I like . When she's here everything seems to run so smoothly.

Where shall we go from here?

I think it is essential that the issues raised within this report are seen in the light of the very positive comments made by residents and staff about life and work at (Nursing Home A). There is always room for improvement in any care situation and I hope that these issues will provide food for thought and a starting point for thinking about future developments. Some issues, such as the quality of food and the purchase of new equipment, are possibly outside the remit of nursing staff to alter. However, other issues could be addressed by nurses and care assistants without having major resource implications. I hope we will have the opportunity to generate some ideas at our meeting.

Appendix XIV Field notes from meeting to discuss first draft of case report at Case Study Site II: Nursing Home B

1.09.00

Visit to meet with manager and clinical nurse manager to discuss my draft report on the home. They were both upset by what they felt were a number of inaccuracies and misperceptions. Following a two-hour discussion I agree that there is an explanation for some of the more negative points I made in the report, particularly the nature of the client group. However, some of their points were questionable and I didn't feel we were able to reach a shared understanding. This leaves me with a dilemma: Do I change my report to something which we can all feel comfortable with (I'm not sure this is possible) or do I risk upsetting them further?

A number of points have occurred to me over the past few weeks. L and G talk about authenticity and the notion of created accounts but I haven't been able to check my interpretation with everyone involved. Maybe the relatives and residents, or even the more junior staff would have felt my account to be accurate. However, there is no way that I am going to get my interpretation past these managers.

I must remember that I have checked out positive interpretations with people as I have been going along.

The clinical manager felt (and I agree) that it was difficult for me to get a true picture by attending only one day a week. She suggested an extended period of full-time observation over several weeks – I agree this may have ensured that I didn't miss events – such as the trained staff meetings, which happen irregularly.

Taking main points in turn:

Their main concern was that some of the concerns I had about the residents not being fully engaged were the responsibility of the resident rather than the staff. H felt that the staff were continually encouraging residents to participate in social activities and to go to the lounge, but it was their choice not to do so. Residents were used to a high level of 'service' in fact some of them had had servants before moving into the home. They sometimes treated the staff like servants and this caused difficulties for staff.

I think the fact that Nursing Home C is an EMI home may have resulted in more of a difference than I had thought. H suggested that in an EMI home, staff are forced to interact more with relatives, particularly when seeking information, due to the difficulties of interacting with residents.

H said that the main assessment takes place when she does the pre-admission visit to check whether they would be happy at (Nursing Home B) and then during the first few days. She said that family members are fully involved in this assessment. Each resident now has the name of their named nurse and key-worker displayed in their room with the date of the next review. H said that relatives are encouraged to

Appendix XIV Field notes from meeting to discuss first draft of case report at Case Study Site II: Nursing Home B

mention any concerns or information to the named nurse or key-worker in advance of the review but that they do not usually attend the review.

Much to my dismay H and T were able to accurately identify the residents' whose quotes I had used in the report. Although I did not confirm that these 'guesses' were correct, I am really concerned about this potential breach of confidentiality. H was particularly concerned about my observations on the lack of information within care plans about residents' social and emotional needs. She said that this information is recorded separately and held by the activities coordinator as he is the person who most needs the information. We had a brief discussion about whether other staff also needed access to this information but I felt it would be inappropriate to take this too far.

Their other main concern was about mealtimes and my observation that residents were unhappy when all people sitting at a table were not served together. H said they had tried a number of ways to deal with this but the problem was that residents did not always arrive at the dining room at the same time.

T was concerned by my observations (based on interviews with relatives) that some were unhappy with the 'corporate' influence on the home and the language of 'customer care'. He said that he never uses this sort of language with relatives (this directly contradicted what two of the relatives had told me) and attributed it to notice of a training session for staff entitled 'customer care' which is displayed on the staff notice board in the entrance foyer. I wondered (not aloud) if the entrance hall is the best place to display information about staff training – again it almost seems an attempt to impress visitors.

Overall, I sensed a reluctance to accept that any of the 'negative' comments within the case study report might have any validity. H and T were both obviously upset: T in particular seemed quite devastated and said that he had thrown the report across the room on reading it. He feels he works extremely hard to create a positive care environment and that this hadn't come across at all within the report. I tried to point out that many of the observations and comments were extremely positive but, I felt, with little effect.

Drawing the discussion to a close, I acknowledged that I had missed some important items of information and indicated that, indeed, this was one of my intentions in asking them to read the report so that I could correct any obvious inaccuracies and misinterpretations. I assured them of the confidential nature of the draft report and offered to modify the draft in light of our discussions.

The modified draft was posted a week later but I received no response.