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LIFE AS A CARE HOME RESIDENT IN LATER YEARS: "LIVING WITH CARE" OR "EXISTING IN CARE."

Glenda Anne Cook

PhD

2007

LIFE AS A CARE HOME RESIDENT IN LATER YEARS: "LIVING WITH CARE" OR "EXISTING IN CARE."

Glenda Anne Cook

Thesis submitted in fulfilment of the requirements of Northumbria University for the degree of Doctor of Philosophy

Research undertaken in Northumbria University,
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Abstract

Despite a widely accepted view of the importance of understanding experience from the point of view of the individual using services in modern western society, there are relatively few studies that have explored day-to-day living in a care home from the older person's perspective. This study aimed to present the voice of the untold stories of care home residents through an interpretative study that was informed by a biographical approach and narrative method. Eight older people who lived in four different care homes in England participated in a sequence of up to eight narrative interviews over a six month period.

Through the process of listening to, retelling and interpreting the residents' stories the resident world was explored. There were three stages to the interpretative process that focused on:- developing a naïve or surface understanding to acquire a sense of the whole sequence of a participant's interviews; a structural analysis that examined the interviews to investigate what the text said and how it was said; and a critical in-depth examination of the interpretation within the wider social context.

The interpretation revealed the unique way that each participant lived in a care home. These older people worked hard to reconstruct their life following the move to a care home and as they lived there. Though the residents were limited by physical, functional and cognitive problems, they developed strategies with the aim of influencing the life that they lived within a care home. Where they were able to implement those strategies they reconstructed their life in ways whereby they 'lived with care.' In this sense they were active biographical agents shaping this phase of their life. This is an alternative biography, to that of older people 'existing in care' as an outcome of care received.

This thesis provides new insights into the residents' world. The overriding conclusion that can be drawn from these stories is that these older people were trying to live as active biographical agents who were instrumental in shaping their own life. They were able to do this to a greater or lesser extent

and the conceptual model of biographical living that has been developed from the resident stories provides a framework to depict the complex interactions that shape an individual's experience in this environment. An inherent feature of this model is recognition that residents can be active agents throughout their lives in care homes. In summary, residents' desire to 'live with care' and this is not only possible, it is achievable.

Acknowledgements

Undertaking this study would not have been possible without the support and participation of many people and I would like to express my thanks to family, friends and colleagues who accompanied me on my journey through the research process that resulted in this thesis. To identify everyone individually is not possible, nor appropriate as this would result in a breach of confidentiality. They all know who they are, and to them I express my deepest appreciation and thanks.

There are a few people, however, that made personal sacrifices to enable me to accomplish this work and for this reason I would like to acknowledge their specific contribution. First, my husband Stuart and children, Daniel and Laurie, who accepted my absences from family life to plan the study, collect data and write continuously over many years. To them I am grateful and express my love for their understanding and patience. I would also like to thank my supervisors, Professor Jan Reed and Professor David Stanley, who have given their expert guidance, unfailing support and encouraged me to finish writing this thesis. Finally the eight older people who freely gave of their time to tell stories of their life as a resident in a care home. Their final years of life were precious and I valued the opportunity to be with them and learn of their lives. In the writing of this thesis I have aspired to be honest and true to the stories that they told.

Declaration

I declare that the work contained in this thesis has not been submitted for any other award and that it is my own work.

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Inserts in the back page pocket

Off print of Cook, G (2006) The risk to enduring relationships following the move to a care home,' *International Journal of Older People Nursing,*1(3), pp 182-185

Off print of Cook, G; Brown-Wilson, C & Forte, D.(2006) The impact of sensory impairment on social interaction between residents in care homes, *International Journal of Older People Nursing*, 1, (4), pp 216 - 224

Chapter 1

Foreground to the study

The UK care home is a relatively recent development within the provision of long-term care for older people. Care homes are facilities that provide accommodation with personal and/or nursing care. These are institutions that exist in the community but are also set apart from it. Reed (1998) draws on Sontag's metaphor of *'the islands of the ill'* to highlight the way that *'islands of the old'* have been created in, and set apart, from wider society. These islands are described as homes, but they are not always seen as home to those who live in them (Oldman and Quilgars, 1999). Whilst there is a widely held belief in Western society that older people want to remain in their own home and fear the need to move to a care home, moving to a care home is a positive option for some older people and a way of enhancing their quality of life (Centre of Policy for Ageing, 1998/9). Such paradoxes permeate current understanding of the nature of life in a care home.

Added to this, there is the quiet, relatively inaudible voice of those older people who have moved to a care home. This thesis provides one vehicle for those living in care homes to speak of their lives and in this way give a view of care home life from the inside. The title emerged from the comments of one of the participants in the research. She indicated that she wanted to *'live'* in the final years of her life, yet she felt that she merely *'existed'* for the most part of her days. Other participants also spoke of their desire to live in the care home and how they strived to develop a life that was meaningful and pleasurable to them. The study reported here builds on these ideas to give an insight into the way that older people experience life in a care home.

This thesis was the culmination of a personal journey that began prior to the research, and a journey that will extend beyond it. So it is fitting that the discussion begins with the origin of the inquiry to highlight the importance of

listening to older people and to develop practice and services that are grounded in their experiences, views and aspirations.

Influences that led to my research interest in the older person's life in care homes

The work undertaken for this study, an exploration of the meaning that older people attribute to their life as a care home resident has emerged from twenty years of practice, teaching, study and research concerning the care of older people. Much has changed during this time. When I commenced my career as a nurse, the landscape for the care of older people was very different to how it appears today.

Twenty years ago the statutory services were major providers of long-term care for older people in the United Kingdom (UK). Long-term nursing care was primarily provided by the NHS through geriatric services in acute hospitals and nursing homes, and personal and social care was primarily provided by Social Services through residential care services. Following reconfiguration of service provision both in statutory and independent sectors this changed. A significant reduction in NHS acute and long-stay beds was witnessed between 1983-1990, contiguous with reduction of approximately forty per cent of older people staying in Local Authority residential homes. Whilst this was happening there was an expansion of residential and nursing home places in the independent sector (Audit Commission, 1997). These combined factors led to the independent sector (including for-profit and not-for-profit service providers) being the major provider for what is nearing half a million older people in care homes in the UK in services that provide both long-term residential and nursing care (Care Standards Act, 2000).

During my career in nursing there has been an increasing emphasis on knowing the person and grounding care in this knowledge. Concepts such as person-centered care, individualized care, relationship-centered care, service user involvement, service user empowerment and ageism are prominent in

the professional and academic literature (see for example Allen, Hogg and Peace, 1992; Jewell, 1996; McCloud Clark and Latter, 1992; McCormack, 1998) and policy and guidance documents concerning the long-term care of older people (CPA, 1984; 1996; DoH 2000; 2001a; 2001b). They have given inordinate emphasis to develop and implement approaches to understand and address the needs and priorities of older people from their perspective. In the care home setting this concerns not only the need for care but of living the latter years of life in a supportive living environment.

Yet all too often I observed a gap between what happened in practice and the theoretical perspectives which informed that practice. Whilst the care of individual residents could be based on their assessed need, this took place within a setting where the routines and practices that permeated the system within care homes dominated the actual care of the individual. The product being that care was provided for a group of residents by drawing on professionally derived or experiential knowledge concerning the care of older people. Through the process of abstraction and generalisation that is inherent in these forms of knowledge, the perspective of the individual is hidden. In many settings the reliance on these forms of knowledge may enable staff to provide relevant and timely care. However, being over reliant on this form of knowledge does little to enable older people to live lives that they find satisfying and fulfilling. This emphasis on care is quite reductionist and focuses attention on prolonging physical life, potentially, to the neglect of enabling the individual to fulfil their desires within their remaining capacities.

The latter point is particularly pertinent when the frame of reference for care is not drawn from the views of those living in care homes, and practice is based on technical professional and experiential knowledge that is derived in other care environments. Until the turn of the twenty-first century in the UK it was widely accepted that nursing qualifications and experience of practice in hospital or community settings were adequate preparation to work in nursing homes and residential care. Added to this, there has been a long history in the UK of unskilled and untrained people comprising the largest proportion of the

workforce that cares for older people in residential and nursing home settings (DoH, 1998).

It was not until I had worked in this environment that I questioned the logic of the transferability of knowledge and skills from acute care and community settings to a nursing home. I found that the knowledge and skills that I had acquired in the hospital setting were inadequate preparation for my work in nursing homes. I felt that, in many of the situations I encountered in this environment, I had inadequate knowledge to support the decisions I had to make. For example, there was a situation where one resident was very confused and often wandered from the home, sometimes onto busy roads. In this situation I was faced with the decision to change the home in ways that allowed him to wander in, but not out of, the home. The majority of the options that were considered resulted in restrictions for other residents. Hence, decisions about promoting the safety of one resident created a situation where the independence of other residents was reduced.

When I sought guidance from colleagues they drew primarily on their practice experience to advise me, yet their knowledge was no more developed than mine. As nurses, we had developed knowledge that equipped us to make decisions about the biomedical and psychosocial problems that older people experience; yet decisions about the long-term care and support of residents required qualitatively different forms of knowledge. It was not until I had entered an academic career some years later that I became aware of the literature concerning residential care and group living that could be utilized to underpin work in care homes. Lack of familiarity with this literature could be attributed to inadequacies of the individual practitioner. Equally it could point to the way that professional insularity limited the evidence base utilised within a profession, which could be to the detriment of those working at the interface between two or more professions.

These combined factors call into question the knowledge base that informs the provision of care in care homes - a setting where nursing, social and personal care converge. In some areas of professional practice, such as

social work education where Certificate of Qualification in Social Work courses included residential care training, relevant education has been available to prepare individuals to undertake practice in residential settings. Equally, there has been specific post-registration education available to nurses specialising in the care of older people. It was not until legislative reform of the registration processes of long-term care services, through the Care Standards Act 2000, and the introduction of the National Minimum Standards for Older People (2001a) that there has been a requirement for specific education and training for those working in care homes to enable them to provide a high standard of care to promote the well-being of residents. With the implementation of the Care Standards Act 2000 there has been the emergence of 'care homes'. These services were previously provided separately by nursing homes and residential care facilities. Hence, there is now a need for knowledge that crosses the boundaries of social care and health professions, and reflects the needs, priorities and concerns of older people living in care homes.

Whilst the recent policy framework goes some way to giving recognition to the need to base practices and services in care homes on skilled, knowledgeable care, it assumes that evidence is available and accessible to support such training and development. The body of knowledge to underpin the care of older people has advanced during the latter end of the twentieth century. However, the need to advance the evidence base remains. The need for knowledge generation is critical at the turn of the twentieth century because decision makers are engaging in both an ideological debate and policy development concerning the provision of long-term care for older people in the UK. In response to this, practice and service provision has been changing. Within these changes the voice of the older person, the care home resident, is almost silent and the danger is that the services that are developing may not be the services that older people want or find desirable.

The factors that have been discussed led me to make a commitment to undertake a study that made known the circumstances of daily life for older people living in care homes. The dearth of work that sought to establish a

means to meet with the viewpoint of residents directed the focus of this work onto the residents' world - to examine the world as they saw it. This work was embarked upon with the intention of making a contribution to the body of knowledge that informed theory, practice and service development within care homes. These factors influenced the general direction for this study but the particular focus was shaped by other events.

Identifying the focus of the inquiry

Some time later in my career when I had entered an academic life I participated in a study that evaluated a quality assurance system, Qual A Sess. This system was developed from research that was carried out in Germany in 1997/8 (there is also a German version of the system, see Klein and Cook, 1998). Qual A Sess enables those living and working in a care home to measure the home's performance in 10 areas of service provision. This is achieved through a self-assessment team, which is comprised of residents, relatives and staff who assess the homes' performance against predetermined standards. The self-assessment process takes place in a structured group discussion where all of the participants are encouraged to state their evaluation of the areas of the home that are under scrutiny. The team members are then asked for the reasons for their judgments and the discussion moves on to reach a group consensus about the home's performance. In situations where the group members perceive that the home has not met the required standard they are asked to make suggestions for improvements and this results in the development of a quality improvement plan (for further discussion see Reed et al, 2003b).

During the evaluation of the Qual A Sess system I observed some of the self-assessment discussion groups and through this I became acutely aware of the diverse opinions that residents, relatives and staff may have of the same issue. Where this occurred there was often a frank discussion about the different opinions that people held and the reasons that they gave to support their views. In these discussions I was struck by the lack of awareness and

understanding of what residents perceived to be important. In one situation, for example, the residents indicated that the shortage of teaspoons in the dining room resulted in the need to share a spoon at meal times. They had mentioned this to the staff on many occasions but the problem persisted. The staff in the group knew that there were adequate spoons for everyone but the usual practice was to put a limited number on each table. The situation was easily resolved. In another situation residents commented on the way that wheelchairs were used as a communal resource. The chairs were not washed between uses by different residents, even following use by those who were incontinent. The residents suggested that wet wipes ought to be readily available throughout the home and communal resources wiped clean following use. The changes to customary practices in both of these situations were achievable and acceptable to both residents and care staff. Indeed, I found that the need to draw attention to either of these issues in such a formal way surprising and concerning; that ordinary uncodified codes of conduct were routinely breached in the care home setting.

On the surface these examples may seem trivial and simply resolved, but the situations were important to the older people as they had lived with these conditions for some time. Other situations were far more complex, and lacked immediate solutions. For instance, residents in one group highlighted their desire to make drinks of coffee or tea for their visitors in their rooms. They wanted to do this as a way of exercising their liberty and entertaining their guests as they would have done in their own home. For the staff, this was a problematic health and safety issue as it posed potential risk to the resident and other residents living in the care home. Care planning also presented areas of conflict, such as managing wandering behaviour and aggression. This was particularly the case when the views of the staff and residents conflicted with each other.

These situations highlighted practical issues associated with living in a group care setting, sharing communal resources and the challenge of balancing the diverse needs within the resident community when planning care for individuals. Moreover they highlighted a gap between the residents' and

staffs' perceptions of these issues and the importance of developing a shared understanding of what is acceptable from the older person's perspective.

The Qual A Sess experience increased my awareness of the diverse perceptions that residents have of the same situation and that they experienced situations where they made compromises about their own preferences to accommodate the needs of fellow residents. The comments from staff indicated that they were not always aware of this diversity or that members of the resident community accommodated for each other's needs. Although the self-assessment groups aimed to promote exchange between residents, relatives and staff in order for those involved to have a greater understanding of the world view of the other participants, it highlighted to me the way that these groups of people had co-existed in the care home, and perhaps continued to do so, with minimal knowledge of each other.

These diverse experiences, in practice and in research, shaped and increased my curiosity to understand more about the resident world. This was a world that I had thought I understood, however, different experiences impressed upon me that I lacked understanding. I had listened to what residents had said but I had not comprehended what they had said - perhaps in a very similar way to those that I had observed. Having knowledge of this was the impetus to undertake an inquiry to examine the way older people describe their life as a resident and what meaning they attributed to this phase of their life.

Although there has been considerable research that has focused on choice of care home, moving to a care home, quality of care, relatives' views of care home life, the cost of care, the nature of work in care homes and regulatory practices, few studies have investigated life in a care home from the residents' perspective. Fewer studies have taken a longitudinal exploration of daily life in these environments. No studies, prior to the commencement of this PhD, have built up an image of care home life, over a period of time, from the stories that older people tell of their daily life as residents. This research therefore seeks to fill this gap and aims to give a voice to the untold stories of

care home residents. Through the process of listening to, retelling and interpreting those stories through this thesis, the world of the resident is revealed. From this, knowledge is generated of what is important to residents, what influences their lives in care homes and what concerns them.

The shape of the inquiry

Although long-term care for older people has evolved in the context of service user involvement, older people who live in care homes have been largely marginalized from the developments that directly affect them. The voice of practitioners, policy makers, researchers and relatives has overshadowed the voice of these older people. In the development of this study I have been influenced by the work and writings of my supervisors and those that have influenced them in their work. They often refer to the following quotation from Jerome:

> 'The methods used to acquire information are such that the subjective experience of ageing is subordinated to the objective accounts provided by youthful researchers. Very little contemporary research addresses the issues of ageing from the elderly person's point of view' (Jerome 1992, p. 4).

This study attempts to respond to such criticism by developing a methodology that elicits and privileges the voice of older people to hear and learn of their concerns and their priorities in their life in a care home. Whilst this is an explicit goal of the research I recognise that I bring many prejudices that provide a continual noise in the background, including personal experiences of practicing, visiting and researching in care homes. Prejudices are considered to be negative influences in many fields of research producing biases within an interpretation of the data, so these are identified in an attempt to bracket them and set them aside. Yet prejudices can also be a strength within a study as they provide a fore-knowledge against which new insights and new understandings can be tested. I have commenced this thesis with a declaration of some of the ideas that I bring to this research, but without these the research would never have begun nor would it have been

completed without the constant reminder from the worlds of policy, practice and research that few people were actively listening to the voice of the resident.

In line with the above argument the understandings that older people have of their experience as residents was privileged in this research by embracing a hermeneutic framework for the study as explicated in chapter 3. Within this overarching philosophical framework, a biographical approach and narrative method led to the generation of a dialogue between the researcher and the researched. The purpose of this was to facilitate a coming together of the views and understandings of care home residents and myself to illuminate life in a care home as it was experienced by older people living in that setting. The interpretative process did not aim to transform how the older people viewed their world, but aimed to make public what had been essentially a private experience. The older people were invited to tell stories of their daily experiences and through dialogue between the participants and the researcher, the interpretation that is reported in this thesis was reached.

Structure of the thesis

In writing this thesis I aimed to strike a balance between describing the experiences and views of the participants and giving a detailed account of the research process itself. As the research progressed I became increasingly conscious of the multiple layers that were embedded in this study - of the individual interacting with their personal, private world in the care home, the complex social environment of the resident world, the interface between the staff and resident world, the staff world, and the interface of the social environment of the care home with the wider community. As I listened to the stories of the older people, I heard messages from the outside (those of the professional, academic, service and policy worlds) differently. This contributed not only to a dialogue between the older people and myself, but also to a personal dialogue with the research process. As a way of capturing the dynamic nature of the inquiry, a decision was made to describe the research

process as my personal story of undertaking this research to make explicit how this interpretation was reached amidst so many other possible interpretations.

In the following chapter a bibliographic overview is presented. The use of literature in qualitative research is a contested area. Whilst some authors may argue that no literature should be consulted prior to embarking on fieldwork (for example, Glaser, 1998), others indicate that an overview of the literature is essential to direct the study without leading it (for example Gadamer, 1975; Hart, 1998). I have already indicated that my personal experiences and knowledge of the literature were a powerful influence in shaping this research. This provided a context, a rationale and an incentive to undertake this study. Thus, I felt that it was important to examine the literature as a backdrop to the study proper as this provided a context for understanding the experiences that the older people described, while also giving a context that may be challenged.

Chapter 3 gives a detailed account of the research process, which is an interpretative study informed by a biographical approach and narrative method. The complexities of accessing and listening to the stories of frail older people in conjunction with maintaining authenticity, credibility and rigour in the research process are explored. Chapter 4 builds on the previous chapter and shifts the focus onto the way that the data was organized, described and interpreted in this study.

The data collected in the study is presented in chapter 5. Here, the stories of the older people are retold as case reconstructions that capture their biography and their views and experiences of living in a care home. These are rich descriptions of their daily lives over a period of four to six months. From these stories their personal narrative of care home living unfolds. These narratives are as individual as each of the people that participated in the study. The idiosyncratic nature of these experiences points to the way that older people living in the same care home can and do live very different lives.

Chapter 6 moves the focus from the individual to examine the themes, topics and issues that all of the participants referred to. From these multiple tellings of stories about care home life, six narrative themes are identified that concern:

- caring for oneself,
- being in control,
- relating to others,
- active users and choosers of space,
- being supported to engage in meaningful activity and
- having an enriched private life.

The notion of receiving care is linked to notions of passivity and dependency and, as a consequence, residents have been viewed as relatively inactive in determining their own lives. The narrative themes and the stories retold in chapter 5 point to the deliberate decision-making and careful planning that the participants engaged in, in an attempt to influence their life in the home. The strategies that residents developed to shape their life in the home form the focus of the latter part of this chapter. In keeping with the emphasis on interpretation of multiple tellings at this point in the inquiry, the emphasis is on examining types of resident-led strategies rather than giving a detailed description of the approaches adopted by individuals.

Throughout chapter 7 theoretical constructions found within academic and professional literature are drawn on to examine the dimensions inherent in each narrative theme. Though these themes are discussed as distinct entities for the purposes of description, in reality the themes are interconnected dimensions of the social environment of a care home. It is individual's construction of each narrative theme that shapes their understanding of what is possible in a care home and the life that they live in that environment. For some people this is a life with care that held for them possibilities for enjoyment, satisfaction and personal fulfilment. For others, this was a life where they were cared-for, lacked control, engaged in few meaningful relationships, occupied space, participated in time-filling activities and lived their lives essentially in public.

The possibility for living alternative biographies, as suggested in chapters 5, 6 and 7, forms the focus of chapter 8. The proposition that older people can live a 'life with care' (a life that is biographically active), or a life 'existing in care' (that is a life that is biographically inactive) is examined. Emerging from this discussion, a theoretical model is constructed to make sense of the observations explicated in the previous chapters. By developing this model, the conceptualisation that an individuals' life is shaped primarily by the dominant culture in a care home is challenged and refocuses attention on the individual, their interaction with the personalities, structures and processes within a care home.

The final chapter considers the importance of older people having the opportunity to develop a life with care that is biographically active. This provides the opportunity for them to be themselves at a stage in their life where they can so easily be deprived of this. The reconstruction of an older person's life, from one of independent living to one of living with care, requires support. Lack of understanding by others - care staff, family and friends - can result in the older person's attempts to reconstruct their life following the move to a care home not being optimised or at worst being undermined. Thus, the thesis concludes with a consideration of the implications of these findings for theory and practice development. This discussion points to the way that these understandings of care home life, derived from the world view of older people, affirms the importance of developing approaches to know, understand and support older people to live the way that they want to in their latter years.

Chapter 2

Bibliographic overview: Historical and theoretical context

Introduction

As discussed in chapter 1, the impetus for this study emerged from my experiences of working in and researching aspects of care home life. This background framed the nature of the study and was integral to it. In line with Gadamer's hermeneutics (Gadamer, 1975, 1976, 1989), as explicated in chapter 3, I reflected on my background as I commenced the study in an effort to become critically self-conscious. This involved understanding literature related to the subject, as this constantly reshaped the understandings that I held about care homes.

Within this study a bibliographic overview was considered necessary to serve three purposes. Primarily I felt that it was essential to understand the literature, theories and concepts that had brought me to this research and had shaped the ideas that I held about life in a care home. Secondly, the overview located the work within a particular historical and theoretical context. Drawing on the ideas of Koch (1999) this was important because people articulate their experiences in relation to others and the world that they know. One way of accessing that world is through the associated literature that provides a written account of that world, which is located in time. Thirdly, the overview provided an approach to identify what was known about the experiences of residents and how that knowledge had developed.

Importantly, many older people who live in contemporary care homes have lived through the history of the development of long term care for older people. This experience shaped their perception of the services that exist today. The workhouse was a reality for some and this was a place that they regarded with fear, a place to be avoided. They lived through the residential

boom of the 1960's in the UK and the asset stripping of older people living in residential and nursing care during the 1980's. Past experiences have the potential to influence the current understandings that people hold of societal structures, so revisiting the literature on the history of contemporary care homes is relevant to this study as a way of acknowledging perceptions of care homes that have been shaped through experience.

The chapter commences with a discussion of the process of undertaking the bibliographic overview, followed by a discussion of the context that shaped the development of the contemporary care home, and then examining what is known about living in that environment.

Literature search, selection, and synthesis

Exploring what is known about care homes and what is understood about living in those environments is a complex process. Contemporary understanding of care home life has emerged from diverse bodies of literature including long term care of older people, gerontology, environmental gerontology, housing studies, institutional living, psychology of ageing and health and social care policy. Developments in diverse fields such as residential care, nursing home care, social work, nursing care of older people, geriatric care, mental health, disability and child care are also important to the development of ideas about care home life. To capture and convey ideas about what knowledge and understandings have developed from these diverse sources a bibliographic overview was undertaken to provide a general description and assessment of the publications relating to the historical development and theoretical context of contemporary care home life, an approach which Belanger (2003) classified as an enumerative approach.

This approach is relevant to this study as it enables the development of an overview of works that collectively contribute to contemporary discourse about living in a care home. The purpose of the bibliographic overview, as described here, is not to examine findings to establish whether they could be

generalised across populations and settings which is the objective of undertaking a systematic review of the literature (Mulrow,1994; Egger, Davey Smith and Altman, 2001; Pearson, 2004), but to summarize and synthesize the arguments and ideas of others.

The bibliographic overview was developed in two stages. First, a search and selection of the literature was undertaken. This was followed by the second stage of summarizing and synthesizing the selected literature. Searching the literature was difficult and complicated by terms and concepts used in the electronic databases that were accessed to identify literature about older people and care homes. There are many keywords that are used to refer to older people, including 'older / old, ageing / aged', 'elderly', 'retired', 'senior, (linked with people / person / citizen'), 'geriatrics' and 'pensioners'. Equally terms that relate to literature about care homes are diverse, including 'care home', 'nursing home', 'residential care', 'geriatric care' as a few examples. The aim of the search for literature in this study was to undertake a sensitive search and retrieve as many relevant items as possible. Searches were carried out on the following databases for the time period 1990 - 2002:

- CINAHL (Nursing and Allied Health)
- PROQUEST
- ASSIA
- CAREDATA

The process of extracting items through data base searches inevitably results in 'false hits,' therefore only those items that related specifically to care homes, residential care and nursing home care were selected for the bibliographic overview. Following identification and selection of the literature the items were retrieved and read. During the process of reading many themes were identified, such as the impact of living in an institution, and the importance of housing to older people. This led onto a subsequent search for literature concerning specific subjects through a range of sources such as library catalogues and electronic databases.

The information seeking process led to the retrieval of diverse literature. In order to summarize and synthesize this work without over-simplifying it, I used the purposes of conducting the bibliographic overview as an organizing framework to illustrate the relationships between different research strands and debates. The outcome of this process is presented in the following two sections of this chapter – the historical and theoretical context of the development of contemporary care homes, and experiences of moving to and living in a care home.

Historical and theoretical context

The UK care home has emerged from a long and chequered history of different forms of services. Care for older people in the UK can be traced back to the late Tudor approach to welfare and poor relief, and through the Victorian Poor Law asylums (the workhouses), to residential and nursing homes that existed prior to legislative reform through the Care Standards Act of 2000. This Act changed registration processes of long term care facilities in the UK. In theory, different levels and types of care can be provided in the same facility. Care homes are now registered to provide a specified volume of nursing and residential placements, and are required to provide board and care for residents in accordance with National Minimum Standards (DoH, 2001a).

Currently the majority of long term care for older people in the UK is provided in care homes (Laing and Buisson, 2004). Though it is difficult to obtain accurate statistics regarding the number of care home residents in the UK, it is estimated that there are approximately half a million frail older people living in these environments with the greater proportion aged 85 and over (Age Concern, 2004).

This history is well documented (Townsend, 1962; Abel-Smith, 1964; Means and Smith, 1985; Peace, Kellaher and Willcocks, 1997; Stanley and Reed, 1999; Netten et al, 2001; Heywood, Oldman and Means, 2002; Netten, Darton

and Williams, 2003). It is not the purpose of this review to critique this literature. The intent is to locate the study within its particular historical context as this context influenced the development of contemporary policy and the services that exist today.

Emergent issues that contribute to contemporary understandings of care home life

Throughout the history of the development of long-term care for older people there has been a transition from custodial provision within institutions such as workhouses, where older people were exposed to poverty, overcrowding and harsh custodial regimes (Townsend, 1962), to the development of an ethos to care for frail older people in dedicated facilities. Peace, Kellaher and Willcocks (1997) argued in their analysis of social policy that the plight of older people living in workhouses gained acknowledgement as understanding of vulnerability and poverty developed during early twentieth century. From this, the idea emerged that the needs of older people were distinct from those of the poor. They required care that addressed frailty as well as health and psychosocial problems.

It was not until the Nuffield Survey on the Public Assistance Institutions (1947) that significant changes to the care of older people were recommended. Namely, dependent older people should be accommodated in small community homes, provided through the State in association with the voluntary bodies, and not in large institutions (Townsend, 1962). The idea that long-term care is best provided in small community based homes persists today. Modern care homes have an average of 30 beds, though smaller homes of 2/3 beds and larger homes in excess of 100 beds exist (Office of Fair Trading, 2005). These homes, though small, continue to be institutions.

There is a vast academic literature on institutions, and within this discourse from the early 1950's onwards, there has been the development of a strand that has exposed the negative and damaging effects of institutional life on its occupants (Bowlby, 1951; Barton, 1959; Goffman, 1961; Townsend, 1962; Robb, 1967; Illich, 1971), which has underpinned the development of an anti-

institutional movement. Though it is not the purpose of this discussion to trace the way that this has played out in UK policy debates, it is important to point out the significant impact that this has had on service planning and delivery. There is now an emphasis on older people receiving care in their own homes in the community, or in homely settings in the community (Griffiths, 1998; DoH, 1989, 1990, 2001a). Indeed, Higham (1994) has argued that the emphasis on community care has resulted in the denigration of institutional alternatives as being universally dysfunctional. Implicit in UK community care policy is the notion that home is important to older people and that quality of life in later life is enhanced when older people are supported to remain at home within their communities. The assumption being that institutional care should be avoided. However, there is some evidence that older people can find living in a care home is better than what they had experienced in their own home (CPA, 1998/9; Oldman and Quilgars, 1999; Lee, 2002). Though there are many influences that shape health and social care policy it does need to be pointed out that the care in the community agenda exists in a social context where payment for long-term care is a major driver and this is also a key determinant of the type and range of services available to older people (Audit Commission 1996; Royal Commission on Long Term Care, 1999; Wright, 2000). These concepts are important to contemporary understandings of care home life, so they are discussed separately in the following section.

With contemporary health and social care policy there has been an emphasis on supporting people to remain in their own dwellings in the community and this has had an impact on the care home population. There is some evidence that the resident population in care homes is ageing and becoming increasingly frail (Campbell, Jagger and Clark, 1993, PSSRU, 2001). This is compounding the physical, mental health, cognitive and functional problems within the resident population. For example, multiple disability and long-standing illness is not uncommon (Bebbington, Darton and Netton, 2001), and recent analysis of resident dependency levels indicate that 75% of residents are severely disabled, this being significantly higher in the female population (Bajekal, 2002). With increasing disability and health problems there is a

growing need for support with self-care tasks, such as assistance with dressing and feeding, in addition to care and treatment. These factors affect life in a care home as they influence what an individual resident can do in their daily life, and also the potential for interaction within the resident community.

Institutionalization and contemporary care homes

The impact that an institution exerts on its occupants has received considerable attention in academic and professional literature since the 1950's onwards. The messages coming through this literature are equivocal. On the one hand the forces and processes within an institution have been identified as having a negative and damaging effect. Alternatively, communal living and group care has been found to have some success. Both sides of this debate have had a powerful influence on current understandings of life in care homes, so the evidence is revisited here.

The idea that institutions are harmful emerged from a series of influential publications that has collectively come to be known as the literature of dysfunction. Beginning in Britain, Barton's monograph, 'Institutional Neurosis' (1959), described the way that some patients experienced adverse effects through their care in psychiatric hospitals. Other work, including Townsend's 'The Last Refuge' (1962), focused attention on older people and detailed the detrimental effects of institutional care upon this group of vulnerable people. Robb's 'Sans Everything' (1967) reinforced this argument through a detailed description of the degrading and dehumanizing experiences of geriatric patients.

Perhaps the most influential in the literature of dysfunction has been Goffman's (1961) study of life in a psychiatric institution. This work portrayed institutional life as divorced from the external world revolving around daily routines that were ritualised. Batch living, where the needs of inmates were processed in the collective with everyone bathing, eating, sleeping and working at the same time, was the norm. Though this may have been administratively efficient and convenient for staff, Goffman's work indicated

that this was a dehumanising experience for residents. Institutional processes resulted in depersonalization, whereby individuals were stripped of all of the usual props that they used to establish and maintain their identity. He observed the way that individuals adapted to institutional life following admission, by making, what he described as, primary and secondary adjustments. Residents learnt the roles and rules that were prescribed for them within the institution, and survival was dependent on being subservient to those rules and doing as dictated by the staff. Though these findings emerged from a study in a psychiatric institution, Goffman's description of institutional life has been uncritically applied to institutions in a wide range of settings with different populations, which has resulted in a negative and stereotypical image of institutional life (Stanley and Reed, 1999).

Much of this discourse on institutions focuses on the institution in isolation from the wider social context. When this context has been taken into consideration in the analysis of residential care for older people it has been found that social processes impact on the older person's quality of life well before the move to a residential institution. Tobin and Lieberman's (1976) study 'Last home for the aged,' for example, found that the alleged adverse effects of institutional practices were present before the older person's entry to the residential home. These were related to the circumstances of the move to a home, such as family breakdown, abandonment and loss. Similar conclusions were reached by Willcocks, Peace and Kellaher (1987) when studying 1,000 residents of old people's homes. They argued that dependency was a continuation of processes that had begun in the community.

In contrast to the discourse on dysfunction, there has been the development of a body of literature that presents the case that in circumstances where institutional processes are controlled, group care can have a beneficial impact on the lives of residents. An exponent of this view, Wolins, in his book 'Successful group care' (1974), argued that the literature of function drew attention to the positive application of group care and group living. This idea had been adopted and translated in many settings such as children's homes, schools and prisons, and across different disciplines. The concept of the

therapeutic community, for example, was based on the idea of utilizing the relationships that exist within an institution and the institutional systems as part of a program of therapy (see Rappaport, 1977; Edgar, 1986; Lees 2004). The therapeutic community enabled individuals to address their health and social problems, thereby returning to independent living.

In the field of physical disability, Miller and Gwynne (1972) undertook a three year pilot study to examine and change institutional care for people living in long term group care. In their work they built on and developed the idea of two models of residential care - the Warehousing model and the Horticultural model. In the Warehousing model the emphasis is on activities that rectify physical malfunctioning and prolong life. Staff, therefore, are required to administer nursing and medical care, and the resident is a passive recipient of their ministrations. In the Horticultural model, the need for care is considered to be a constraint to be addressed. Here, the emphasis is on developing the capacities of the individual and providing opportunities for them to fulfil their desires. This model was found to have a positive impact on resident's well-being, increasing their involvement in decision-making and enabling them to fulfil personal objectives. There are, however, limitations of both of these models in their pure form. For example it is detrimental to ignore the physical limitations of the individual and raise expectations that cannot be fulfilled.

These bodies of literature, when assessed together, suggest that care in total institutions can, but does not inevitably, result in catastrophic negative outcomes for residents. These ideas persist into contemporary old age care. Evidence continues to be generated of the negative and damaging impact of institutional life for older people living in long-term care facilities. Diamond's (1992) qualitative study of the day-to-day experiences of nursing assistants working in an American nursing home drew attention to the way that care staff have power and control over residents. He argued that the structures and processes in a nursing home transformed residents from '*acting beings into acted upon beings*' (1992, p. 127). British literature also indicates that institutionalization continues to exist in long-term care homes with residents

being transformed into passive beings who become the focus of the work of the care staff (Lee-Treweek, 1997; Eyers, 2003).

Equally, there is discussion in the literature that care homes can provide functional, supportive and thriving living environments for older people. Cantley et al's (1999) work concerning the development of small group homes for older people with dementia, for example, highlighted the way that residents can be supported to participate in decisions about their daily lives and functioning of the home. Through this type of involvement the frail older people living in these homes were able to continue to contribute to their community. Recent developments in USA, known as The Eden Alternative, seek to transform sterile long-term care facilities into places where older people continue to enjoy a stimulating life (Barba et al, 2002; and Tesh et al, 2002). Such innovative services reflect the attention that has been given to developing supported living environments that are acceptable to older people as an alternative to receiving care within their home. These developments are taking place in a context where there is an increasing acceptability of communal living within the independent older population across the Western world (see for example Baars and Thomese, 1994; Croucher, Pleace and Bevan, 2003). Accounts such as these suggest that there is an alternative to the routinized institution. This literature, however, is largely descriptive with little empirical evidence of the impact that these environments have on the daily life of residents.

In summary, the notion of care homes as functional or dysfunctional environments are important concepts that run through contemporary literature on life in care homes. Current evidence has largely been generated through qualitative observational studies pointing out the existence of care homes that are de-humanising, ritualized care environments, with some evidence that desirable care facilities do exist.

Attachment to place and the meaning of home to older people

Alongside the emergence of the contemporary care home, there has been increasing interest in the importance of place and the meaning of home to older people (Gurney and Means, 1993; Peace, 1993; Heywood, Oldman and Means, 2002). The significance of this is highlighted in the development of the discipline of environmental gerontology, which provides a way of conceptualizing and investigating the relationship between ageing and attachment to place (Wahl, 2001). This is an important area of research with respect to understanding the experience of older people moving to a care home setting and their aspirations for living in that environment (Warnes, 1982; Willcocks, Peace and Kellaher, 1987; McAuley and Usita, 1998).

The importance of place in later life

For older people there is a close link between the locality that they live in and ideas of self. Cuba and Hummon (1993), for example, argue that people identify with a place at various levels such as dwelling, community and region. They construct their identity through their experiences and represent that identity through the characteristics of a specific location and reference to that place.

Knowing and trusting the people who live close by has been found to be as important as familiarity with the immediate environment (Depres, 1991, Sixsmith and Sixsmith, 1991). This is particularly important to the development of social relationships, which are forged through contact with others in the local community, or as the result of chance contact in the street or in the garden. Through such contact, deeper relationships may develop. Lawton and Simon (1968) found through sociometric surveys and preoccupancy interviews with 464 participants, that proximity is an important factor in the way that people develop their social structures. For older people who are less mobile, proximity-bound friendships become particularly important. This is supported by Wenger's (1990) qualitative study that found that older people build up networks of friends and neighbours around their

homes. These relationships serve different purposes including support and contributing to their sense of social identity.

Within this literature there is an emerging theme that the move to a care home is more than a change in accommodation, it involves relocation within a locality or to another locality. Older people may move to a home within a different geographic locality to be near their family. This may be their choice. However, this may be the choice of family members who exercise considerable influence in decisions about the selection of care home (Dellasega and Mastrian, 1995; Nolan et al, 1996; McAuley; Travis and Safewright, 1997; Ryan and Scullion, 2000; Cook et al, 2001).

Whilst these types of moves may draw families near to each other, they have the potential to disrupt friendships and participation in activities in the familiar community (Cordon and Wright, 1993). The importance of familiarity with a home and its locality was highlighted by Reed, Roskell Payton and Bond (1998) when reporting on an ethnographic study where older people had been interviewed prior to moving to a care home and three times afterwards. They found that issues of place were important in decisions about choice of home to retain a sense of belonging and attachment to their community, and as a way of identifying with other people in the care home as a foundation to getting to know them.

The link between locality and home

Whilst an individual's personal dwelling may be located in a particular locality, the notion that home extends beyond the boundary of the physical perimeter of the building has developed. In a study conducted by Rowles (1978, 1981) it was identified that older people arranged their home to enable them to link with others outside of their house. They placed seating near windows where they could observe people passing or to allow others to see them. From these observations Rowles developed the concept of the '*surveillance zone*,' which is the space that people can see from their own home.

This idea has been extrapolated to the care home context where the zone outside of a home is considered to be an extension of this environment. The work of Parker et al (2004) highlights the importance of the location of a care home in enabling residents to experience a sense of connection to their local community. The position of windows and seating allows or inhibits residents to observe and interact with the neighbourhood. Being able to do this and to connect to the external environment has been identified as an important determinant of quality of life in care homes (Chalfont, 2005).

Meaning of home

As well as attachment to communities and regions, older people have a deep attachment to their homes (Cooper, 1974; Saunders 1989; Gurney and Means, 1993; Golant, 1998; Heywood, Oldman and Means, 2002). Home is more than a building, it has both existential and experiential dimensions, with physical (objects, spaces, boundaries), social (involving people, relationships and interactions) and metaphysical (significance ascribed by individuals and communities dwelling in the home) elements.

Gurney and Means (1993) point to the importance of the experiential dimension of home and suggest that this may have more influence on attachment than the physical or financial characteristics of the house. Several aspects of the meaning of home may contribute to this. First, there is a temporal and historical aspect to home, giving rise to a sense of continuity in life to the occupant. Every feature of a home confers a set of memories - decor, furnishings and objects - that are both symbolic and representative of self and a lifetime's achievement. Ekstrom (1994) described the importance of this to the development of self-hood in the following way:

> 'We ascribe a social meaning to objects, house, furniture, streets and parks by directing our actions towards them and constantly referring to them in social interaction. The objects acquire meaning. They convey attitudes and values and are integrated into our subjective understanding of reality' (p.374).

There is also the spatial perspective that a home provides. In this space, our personal territory, there is a degree of certainty and relative independence.

Personal control can be exercised in this environment, in its most simple form there is control over who can enter the environment and what they do there (Stea, 1970). Reed, Stanley and Clarke (2004) argue that there is a pervasive view within the UK that as people age they progressively require less personal space. This view is derived from the notion that older people require accommodation that is manageable, and this is associated with smaller scale housing. This, in turn mirrors the deficit model of ageing where the older person's physical world is considered to shrink proportionally in relation to the atrophying aging person. This idea has been challenged in recent debates that draw attention to the negative impact on quality of life of limited space within a residential environment (Peace, Kellaher and Willcocks, 1997). Indeed, much of the emphasis on the lived environment in the setting of the National Minimum Standards (DoH, 2001a) has been on spatial issues in care homes, possibly to the neglect of developing standards that are concerned with the quality and meaning of that space.

Early literature in social ecology drew attention to the way that people interact with their space to give meaning to it. Lawton (1970), in an analysis of the literature, highlighted the importance of space to social relationships and social functioning. Here the idea emerged that older people altered their environment or varied their behaviour in the service of their needs. In these ways older people adapt to living in their environment. Lawton concluded that more competent older individuals are more able to adapt their environment to their needs and those with reduction in their competence are more behaviourally dependent on their external conditions. Pastalan and Carson (1970), in an analysis of the spatial behaviour of older people, argued that they constantly and actively work to change the neutral space that they occupy to transform it into behaviourally significant and meaningful space by structuring their space and the objects within it.

Oldman and Quilgars (1999) suggest that there is a tendency in the mainstream of work to romanticize the concept of home and attachment to this environment in old age. They conducted interviews with two groups of very frail older people, some who lived at home and some who lived in a

home, and found that living at home can be bleak - the social isolation they experienced was depersonalizing and dehumanizing. For older people who require support and care and have lived in impoverished circumstances, Oldman and Quilgars suggest that relocating to different accommodation, such as supportive living housing and care homes can be a positive move and not the negative experience that is often portrayed (see also Iwasiw et al, 1996; Reed and Payton, 1996).

The meaning of home in later life is complex and multidimensional. There is considerable evidence that home is important to older people for reasons that extend beyond the physical space that the building provides for living out daily life.

Care homes: home-like or care communities

The importance of the concept of home in later life has been reflected in the practice literature through its emphasis on culture at the level of the care home organization. In the UK, creating a *'home-like'* or *'domestic-like'* environment in a care home is promoted both in practice literature and health and social care policy as conducive to enhancing the residents' quality of life (DoH, 1989; Savishinsky, 1991; Peace, Kellaher and Willcocks, 1997; Stafford, 2003). This notion of creating homeliness has focused attention on the furnishings and fabric of the building and the practices within that environment (Reed, 2006). In the documents 'Home Life' (CPA, 1984), 'Homes are for living in' (DoH/SSI, 1989), and 'A better home life (CPA, 1996), emphasis is placed on the importance of the values of privacy, dignity, choice, rights and fulfilment in care home life as they would exist in their own home. The idea being that residents can be themselves in a home and optimize their well-being.

Though policy and practice documents promote freedom of choice and responsiveness to individual need, residents inevitably encounter restrictions in their life in a care home. For example, the majority of meals are provided in

homes at set times. This has the consequence of creating a routine around the mealtimes that has more to do with the functioning of the home than the preferences of individual residents. This example suggests that the provision of a homely environment is set against a background of institutional systems and processes. Willcocks, Peace and Kellaher (1987) highlighted the paradox of creating home-likeness in group care environments in their analysis of life of 1,000 residents in supportive care environments in the UK. They warned that there was a need not to be dismissive of the view that the ideal of providing a homely setting is a genteel facade behind which institutional patterns, not domestic ones, persist. More recently, Peace and Holland (2001) have pointed out the difficulty in achieving home-likeness in group living environments, therefore questioning the appropriateness of the model of the care home as home. A care home is a residence to the occupants, yet at the same time it is a group care environment and a workplace. In recognition of this, recent research has focused attention on developing models that provide an alternative to that of care home as home.

Davies (2001) doctoral work has contributed to the development of the idea of a care home as a community, with each community creating its own distinctive climate. This qualitative study identified three types of community within the contemporary care home sector in the UK: the '*controlled community*'; the *'cosmetic community'*; and the *'complete community*.'

The '*Controlled community*' reflects many of the characteristics of the Warehouse model described by Miller and Gwynne (1972) that has been discussed previously. The key objective of the care home in this model is to maintain residents through processes that are controlling and relationships between staff and residents that are hierarchical.

The second type of home is the '*Cosmetic community*'. Davies argues that this type of community is derived from contemporary service industries. The central objectives of these types of homes are to achieve customer satisfaction and to meet service specification through service outcomes and to

attain profit margins. In this type of environment staff attend to the needs of residents, the customers.

In the '*Complete community*' Davies states that *'care is orientated toward enabling and nurturing residents to achieve their optimal quality of life and is person centred'* (p.214). Relationship-centred care is a key feature of this type of home and, as well as fostering effective team working within the home, family involvement in care is fostered. The Complete home is a community within the wider community and residents are actively encouraged to sustain their links with the local community. This work not only points to the existence of different cultures in care homes, with the possibility that homes fall within and across these categories, it also demonstrates a relationship between the type of home and different types of resident experience. The 'Complete community', is heralded to be consistent with the most positive resident and relative experience.

In a development of the model of care home as community, which was based on a review of the literature as well as the empirical work described above, Davies and Brown-Wilson (2006) explicated the importance and value of creating enabling, supportive and restorative long-term care communities. These environments maintain the older person's identity, provide opportunities for taking part in meaningful activity, facilitate interaction between community members based on reciprocity, provide a built-environment that contributes to the well-being of residents, and facilitates residents' participation in shared decision making.

This body of work has focused attention on understanding care homes as organisations, and the influence of organisational culture on resident experience. By focusing the orientation of this work on care home culture, understanding the interaction between the individual and the environment that they live and work in has been somewhat neglected. Through the shift from drawing comparisons between care home and home, to promoting home-like domiciles in group care settings, the model of care home as community has offered an alternative way of conceptualizing care home. There is a need for

further work, however, to understand the perceptions that older people hold of those different types of communities.

Experiences of moving to and living in a care home

Moving to a care home

The transition to a care home is described in the literature as one of the most significant and anxiety provoking relocations in later life (Tobin and Lieberman, 1976; Biedenham and Normoyle, 1991; Nolan et al, 1996; Lee, 1997; Kellett, 1999; Lee, 2002). Lee's (1997) study of 20 community living older Chinese people suggested that prior knowledge of residential care heightened concerns about residential living. These people had learned much about the negative aspects of care through second hand accounts from relatives and friends.

The move itself is associated with negative images of failure: failure to maintain independence; failing health; and failing support networks (Victor; 1992). Hence, there is a stigma associated with being admitted to long-term care, so older people and their carers tend to leave the decision to move to a care home as their final option (Allen, Hogg and Peace, 1992; Higgs and Victor, 1993; Dellasega and Mastrian, 1995). At this point admission to a care home often occurs at a time of crisis, following illness, deteriorating health, hospitalization, illness/death of a spouse/carer (Chenitz, 1983; Willcocks, Peace and Kellaher, 1987; Dellasega and Mastrian, 1995; Ryan and Scullion, 2000; Davies and Nolan, 2003) which exacerbates the stress and anxiety inherent in this situation.

Chenitz's (1983) grounded theory study has been influential in identifying the relationship between features of the move to long-term care and post-placement adjustment. She argued that four basic conditions shape the older person's later adjustment. These being the perceived importance of the move in maintaining a sense of independence, autonomy and control; whether the

move was desirable or the choice of the older person; whether the reason for the admission was judged as legitimate; and the time and duration of the placement. Furthermore, recognizing the move as the only real option available to older people culminates in an acceptance of the admission to long-term care. According to Nolan and Grant (1992), describing acceptance only in terms of submission does not allow for the possibility that placement in long-term care may be a positive choice for some older people.

Whilst Nolan et al (1996) argued that older people do make a positive choice to move to a care home, this is not the case for the majority of people (Allen, Hogg and Peace, 1992). Often the decision to move is suggested and/or made for the older person by a relative or professional. In some cases older people may not visit a home or receive information about a home prior to moving (Neill, 1989; Bland et al, 1992; Booth, 1993; Johnson; Schwiebert and Rosenmann, 1994; Nay, 1995; Office of Fair Trading, 1998). Consequently, older people feel that they are alienated from key decisions about their future as they experience lack of involvement and loss of control (Sandberg, Lundh and Nolan, 2001). When older people are instrumental in making decisions this has been found to have positive impact on their perceptions of the home and their subsequent adjustment to care home living (Johnson, Schwiebert and Rosenmann, 1994; Reed et al, 2003a).

In acknowledgement of the interplay between pre-placement experiences and later adjustment to this, there is now an emphasis in the literature on planning for a move and involving the older person in decisions about the move. Informing older people of the options available to them, supporting them to make informed decisions through trial visits and provision of information, enabling them to express their views and preferences and involvement in the selection of care home are issues that have received much attention (Kellaher, 2000; Counsel and Care, 2000; Sandberg et al 2002).

Adjusting to care home life

The move to a care home is a significant change in lifestyle for an older person. The transition to living in long-term care commences prior to the move and the evidence indicates that adjustment continues after relocation has occurred. Hence, transition to care home life is now recognized as a process rather than a unitary event (Kahn, 1990; Nay, 1995; Reed and Roskell Payton, 1996; Wilson, 1997).

With the exception of Kahn (1999) and Iwasiw et al (2003), studies have focused attention on the reactions of the older person during the early stages of residential life up to six months. During the phase following relocation, residents have been observed adjusting to their new living arrangements and their newly acquired role. In Reed and Roskell Payton's (1996) ethnographic study interviews were carried out with older people prior to the move, immediately following admission, and at six weeks and six months. During the initial phase of moving to and arriving in the home older people were observed engaging in a process of '*maintaining continuity of the self*' by identifying links between their new and previous home. Though the link may have been tenuous, such as knowing the history of the home, the act of constructing familiarity with the home was important in that it enabled the new resident to engage in conversation with fellow residents. New residents were active in the way that they '*managed the self*' during the first few months following admission. They found out about the conventions within the home and the implicit social codes of conduct between residents. During the following phase of settling into the home, residents focused more on establishing themselves in the care home community. This involved building on and developing relationships formed following admission.

The process of moving-in, settling-in and fitting-in to the care home community appear to dominate the early phase of adjusting to care home life. Iswasiw et al's (2003) longitudinal narrative study of six older people during the first year following the move suggests that later adjustment focuses on maintaining previous relationships and establishing new ones, reflecting on

and appraising their life in the home and seeking ways to maintain their identity in long-term care.

Collectively this literature portrays older people as an active being, working to reconstruct their life throughout the transition to living in a care home. There is some evidence that staff are not always aware of the efforts that residents make to adjust to care home life, the danger being that residents are not always supported in their efforts (Reed and Roskell Payton, 1996).

Continuing to reconstruct life in a care home

Kahn (1999) reached the conclusion through a nine month ethnographic study of a 145-bed nursing home for Jewish elders in the Western United States that adjustment was more than a feature of early residential life. He argued that older people continue to attempt to make the best of their situation by *'a concerted and continual effort to reframe and reconstruct the social environment'* (p. 130). Yet the image of older people engaging in an active process of adjustment throughout their care home life contrasts with the stereotypical image of residents as passive recipients of care (Diamond, 1992; Lee-Treweek, 1997; Eyers, 2003). In this literature residents are dependent on the support of staff and their daily lives revolve around institutional processes.

These messages are contradictory. It is unclear from this work whether older people's interactions with the social system of the care home changes at some point along the trajectory from entering to leaving the care home. Paternity's (2003) ethnographic study of the experiences of six older people living in a nursing home in California, USA, for more than one year also provides evidence of the way that resident's lives were embedded in the daily care-giving routines of institutional life. Her work, however, suggested that older people were very active in the way that they responded to institutional processes. Their actions did influence their interaction with staff and their life in the nursing home. Her analysis led her to conclude that residents actively

contribute to the development of institutional titles or institutional roles such as *'time-consumer,' 'feeder,'* and *'trouble-maker'*. Some of these titles/roles, for example *'the feeder'*, may be construed as an older person being a passive recipient of care, however it was the older person that actively shaped the perceptions that were held of them. She argued that residents:

> 'construct identity and personhood within, and often against, the descriptive imperatives and tendencies of the institution. Seeing the nursing home experience in this way presents residents as biographically active in designating what it means to be a nursing home resident' (p.59).

In contrast to the literature of the early phase of residential life, this analysis of the way that older people reconstruct their life in long-term care does not allow for the possibility that residents can reframe their life as a positive expression of their personhood that is consistent with their earlier life, within different living arrangements. This analysis originates from the staff world through an observation of the happenings within the resident world, so there is a need to develop understanding of these observations from the perspective of older people themselves.

Living in a care home

Whilst living in a care home has been compared to living in one's own home, the evidence clearly indicates that these are very different experiences (Higgins, 1989; Oldman and Quilgars, 1999; Heywood, Oldman and Means, 2002). In Kahn's (1999) ethnographic study of Jewish elders living in a nursing home it was identified that residents experience ambivalence concerning the nature of their living environment. On the one hand the nursing home was their home, the residence that provided security and care. Yet the restrictive nature of daily life that revolved around institutional processes led residents to conclude that it was not like home. It was a communal living as well as a work environment where features of institutional life persisted. Although institutional life has been described as a de-humanising and debilitating experience at its worst, Kahn's study indicated that this could be

an alternative and acceptable style of living for older people (see also CPA, 1998; Oldman and Quilgars, 1999; for similar conclusions).

As a consequence of living in a communal environment, residents experience vulnerability as they rely on the support of staff for personal as well as health needs, loss of identity when they are unable to fulfil social roles acquired throughout life, loss of control when they are unable to carry out the decisions that they make, assault to their autonomy and the challenge of living amongst strangers. These are themes that Davies (2001b) and Lee (2002) identified through their separate, detailed reviews of the care home literature prior to 2000 and between 1970 and 2000 respectively. Lee's (2002) review acknowledged the substantial body of knowledge that has developed since 1970 on pre-placement experiences and the transition to care home life. Less is known, however, about the experiences and adjustments to events in day-to-day life. The recent literature review carried out within the UK National Care Home Research and Development Forum (NCHR&D Forum, 2006) also highlighted the lack of evidence to inform an understanding of quality of life from the perspective of care home residents. Each of these themes is briefly discussed to give an appreciation of the literature concerning living in care homes.

Loss and vulnerability

Transition to care home life involves experiencing many types of losses – loss of lifestyle, role, privacy, independence, control, home, neighbours and personal belongings to name a few (Nay, 1995; Iwasiw et al, 1996; Fiveash, 1998: Marcoux, 2001; McKee, Harrison and Lee, 2005). Living in a care home poses the risk of further loss such as breakdown of social networks that are reliant on proximity to other people. Added to this is the likelihood of further physical, functional and mental deterioration that increases the possibility of greater dependence on care home staff for personal daily living activities (Netten et al's, 2001; Bajekal, 2002).

It is these accumulated actual and potential losses that are significant to residents (Lloyd and Cameron, 2005). Older people are unable to influence or

even to predict with any certainty many of these aspects of their life so they feel powerless, which contributes to their sense of vulnerability as a resident. Davies (2001b) review of the literature highlights the way that other problems such as sensory impairment and communication difficulties compound the sense of vulnerability that frail older people experience in care homes.

There is growing evidence that it is not only the material or functional loss itself that is important to older people, it is the individual's perception of the significance of that loss, and what it symbolizes to them, that leads to negative feelings such as a devalued sense of individuality (Kahn, 1990; Nay, 1995; Lee, 2002). In the case of an older person living in a care home their loss of their home can be evaluated more in terms of loss of security, control and self-identity in the way that the experiential dimension of home is representative of self as previously discussed.

Living in a care home is not necessarily evaluated by residents as a negative experience. There is some evidence that care homes can provide a sense of relief to older people that they are living in a safe and secure environment. Also, the presence of other people can be important to some people who experienced loneliness at home (Reed and Roskell Payton, 1996; Iwasiw et al, 1996; Lee, 2002). In the practice literature it is increasingly recognized that older people need to be supported through the losses that they experience as a resident to enable them to maintain or reconstruct their identity and regain a sense of control in their lives (Davies, 2001b; Bridges, 2006).

Loss of control and diminished autonomy

Frail older people are disadvantaged by health problems that potentially limit their participation in decision-making. Communication, sensory, cognitive and functional problems all reduce an individual's ability to make independent decisions (McCormack, 1998). Added to this, conversational barriers between older people and their carers has been found to limit participation in decision-making (Kaakinen, 1995; The Health Advisory Service 2000 1998).

Research by Agich (1993) and McCormack (1998) has highlighted the difficulties with a simplistic understanding of autonomy as an individual's ability to make independent decisions. Older people living in long-term care are no longer independent. Their need for support with daily activities and personal care results in the necessity to negotiate personal need with care staff. This is not entirely straightforward when such negotiations take place within group care settings where the needs of others in the resident community require consideration and there are constraints of time and resources.

Viewing decision-making capacity as the ability to exercise decisional autonomy is also problematic for older people. They may have the ability to express preferences, but other problems, such as limited mobility, may limit their ability to carry out their choices. Collopy (1988) has drawn a distinction between types of autonomy which points to different ways that autonomy can be thought about. For example, Collopy identifies '*decisional autonomy*' [the ability to make decisions without external constraint or coercion] and '*executional autonomy*' [the ability and freedom to act on decisional autonomy]. Hence, when an older person experiences changes in their physical abilities they may retain the capacity to decide while lacking the ability or freedom to execute decisions.

Peace, Kellaher and Willcocks (1997) pointed to the importance of recognising this distinction between different forms of autonomy in residential care settings because it enables practitioners to support older people to exercise control within their remaining capacities. Residents may continue to make choices, thus exercising decisional autonomy, however other people may be required to give support to carry out those choices. Whitler (1996) argued that staff in long-term care settings have a moral obligation to provide the conditions that enable older people to participate in negotiation of their care and suggested that they could do this through the use of '*assisting behaviours*'. These are variously described as personalising, shaping instrumental circumstances, informing, considering factors to reach a decision about it, assessing the decisional capacity of an older person to make the

decision in question, persuading and mentioning opportunities. Being able to exert control by influencing decision-making is an important determinant of quality of life (Kane et al, 1997). However, the evidence continues to indicate that this continues to be an aspect of institutional life that is severely curtailed (McCormack, 1998; Davies and Brown-Wilson, 2006).

Relationships

Social relationships in later life has been identified as an important determinant of self-perceived quality of life, life satisfaction, self-esteem, well-being, continued functioning and health (see for example, Hooyman, 1983; Wellman and Hall, 1986; Lee and Ishii-Kuntz, 1987; Traupmann, Eckels and Hatfield, 1992; Farquhar, 1995). The evidence also indicates that relationships between residents, family, friends and staff are important to care home residents (Reed and Roskell Payton, 1996; Mattiasson and Andersson, 1997; Peace, Kellaher and Willcocks, 1997; Davies, 2001a) with these impacting on quality of life and life satisfaction (Grau, Chandler and Saunders,1995; Bowers, Fibich and Jacobson, 2001; Tester et al, 2004). Indeed the way that residents form their perception of a '*good day*' within a care home is highly influenced by their relationships with care home staff (Grau and Wellin,1992). This is not surprising given that many older people rely on care staff for assistance with many of their activities.

In recognition of the way that the move to a care home threatens relationships between older people and their families, Davies (2001a) explored the views of 48 people who had assisted a close relative to move to a care home. She identified that relatives seek ways to maintain contact. Staying involved does mean the end to familiar patterns of interaction and establishing new ways of being together, such as making regular visits, contributing to care-giving and taking the older person on outings, which are greatly valued by residents (Kellett, 1999; Ryan and Scullion, 2000; Davies, 2003; Iwasiw et al, 2003). On the basis of a literature review Nolan and Dellasega (1999) concluded that care home staff play a key role in maintaining relationships between older people and their families. Creating a welcoming environment that encouraged and supported visiting, clarifying roles and responsibilities, valuing the

contribution of family to care planning and supporting family members to cope with the loss and guilt which is commonly experienced, were different types of interventions facilitating ongoing involvement.

The literature concerning relationships between residents is less well developed. Though there is evidence that residents can dislike fellow residents and be irritated by them (Hubbard, Tester and Downs, 2004), there are reports that residents value the opportunity to get to know and develop intimate relationships with others (Mattiasson and Andersson,1997; Kane, 2003). Developing relationships with fellow residents is compounded by many factors including communication difficulties, sensory impairment and limited mobility (Davies, 2001b; Davies and Brown-Wilson, 2006), and this can result in residents experiencing isolation in care homes. Although residents can develop relationships with each other, often staff are unaware of these. Consequently resident's efforts are unacknowledged, viewed as insignificant or go unsupported (Reed and Roskell Payton, 1996; Stanley and Reed, 1999; Davies, 2001a). In spite of the importance of social engagement, developing understanding of ways to facilitate relationships between residents that are based on factors other than mutual interest has been somewhat neglected.

Quality of life

Until recently much of the practice literature has focused on examining the technical quality of care (Redfern 1993; Nolan et al, 2001; Davies and Heath, 2006) and relatively little attention has been given to understanding good quality of life in the context of older people living in care homes nor approaches to enhance this aspect of human need (Kane, 2001, Nolan, Davies and Grant, 2001; NCHR&D Forum, 2006). Although all of the issues discussed up to this point impact on quality of life, there is little consensus about key determinants. The main reason for this is that different things are important to different people in different circumstances (Farquhar, 1995). Research, by Raynes (1998) for example, has found that the determinants of quality of life differed between older people and other groups such as professional carers, which points to the importance of identifying what older people themselves value.

In a recent literature review that explored older peoples' views on what constitutes comfortable healthy ageing, and the associated group discussions with older people, Reed et al (2003c) argued that it is important to adopt inclusive definitions of health and quality of life that moves beyond physical functioning. Their work pointed to the importance of acknowledging that growing older involves a number of difficulties, not least living with physical discomfort, decline and ill health. When these factors are taken into consideration older people can experience quality of life through being able do those things that they want to do. These ideas are particularly relevant to care home residents who live with high levels of limiting illness and disability. There are very few studies that have investigated quality of life from the perspective of older people living in long-term care facilities. Amongst these is Tester, Downs and Hubbard (2000) ethnographic study in the UK explored frail (with physical and/or mental conditions) older peoples' views of their quality of their life in institutional care through interviews and naturalistic observation. They found that the key components older people perceived to promote or inhibit their quality of life clustered around four interrelated themes – sense of self, the care environment, relationships and activities.

In recognition of the importance of quality of life as a key goal of long-term care, Kane et al's (2001, 2003) research in the USA has sought to develop instruments to measure quality of life as reported by older people that may be utilized in long-term care quality improvement processes. In this program eleven domains of quality of life are distinguished – namely security, comfort, meaningful activity, relationships, enjoyment, dignity, autonomy, privacy, individuality, spiritual well-being and functional competence. These researchers conclude that quality of life can be measured from resident self-report yet there is the need for much more work in this area.

Whilst the discussion has pointed to the distinction between quality of life and quality of care, it is important to acknowledge that these are not completely separate. Quality of care does impact on quality of life. Researchers at Sheffield University have created a model, known as the '*Six senses*

framework', that identifies what needs to be in place for quality of care in long-term settings (Nolan et al, 2001; Nolan et al 2002; Davies and Heath, 2006). The senses being: a sense of security, belonging, continuity, purpose, achievement and significance. Inherent to this model is the notion that understanding of the experiences of older people, families and staff, and ensuring that all stakeholders in the care triangle achieves fulfilment in each of the senses, communication and partnership working is facilitated. This in turn improves quality of care and enhances quality of life.

It can be concluded from this brief overview of what is reported in the literature about older people's experiences of moving to and living in a care home that a substantial knowledge base is developing yet significant gaps remain. There continues to be a need to understand how the older person experiences daily life in a care home and the dynamics that affect their quality of life within this group care environment.

Summary

It is clear from the bibliographic overview that care homes in the UK are the contemporary societal institutions for the provision of long-term care for older people. These institutions bear a complex legacy of cultural change that shifted from incarceration to care of older people, social reform of long-term care services, and a changing landscape that has resulted in a mixed economy of state-provided, not-for-profit and for-profit long-term care services. Whilst these changes were brought about by many factors, the bibliographic overview highlighted the important role that researchers and practitioners played in exposing the damaging and degrading effects that institutions can have on a resident population. Though the literature of dysfunction was developed some time ago and was generated from studies about institutions that existed at that time, it has had a marked impact on reform of health and social care institutions and the way that institutions are now viewed in society. In the field of care home research studies continue to generate evidence that these environments can be de-humanising, ritualised care settings if institutional processes remain unchecked. Whilst findings such

as these have stimulated researchers to continue to understand institutional processes in order to continue to bring about improvement in these conditions, equally these findings reinforce stereotypic negative images of care homes that older people hold.

In line with the growing literature of function, which points to institutional living having a positive impact on residents when institutional processes are controlled, contemporary care home research has focused its attention on developing understanding of the climate of a care home in an attempt to foster the development of communities of care that enable older people, who require long-term care, to thrive and live the remainder of their life with dignity. It is important to the development of care homes, to support these facilities to be positive long-term care living environments that are acceptable and appropriate for older people. By focusing on care home culture and attempting to understand this at the level of the organisation, however, it could be argued that this has resulted in minimal attention being given to understanding the interaction between the individual and the environment in which they live. With increasing literature pointing to the active way that older people reconstruct their life following the move to a care home, and limited understanding of these processes, it is important that knowledge continues to develop of both the institutional and individual level of experience.

With respect to literature that has examined the individual level of experience, much of the care literature work has focused on the experience of moving to a care home and the adjustments that older people make during the settling-in period of care home life. Less is known about older people's views of their experiences and adjustments to events in day-to-day life following the initial phase of settling-in.

In the main care home studies have adopted methodologies that require limited engagement with older people such as single interviews to investigate a particular aspect of care home living. Though these studies have led to the generation of knowledge about care home life, methodologies that involve only brief encounters between the researcher and those being researched do

not facilitate the building of a relationship that is conducive to the exploration of sensitive topics. When researchers complete their brief episodes of data collection they leave. Residents, however, live in the home prior to and following data collection, which creates the possibility that this may affect disclosure during the research encounter. Methodologies that facilitate engagement beyond a brief encounter provide the opportunity for researchers to build a relationship with participants and this opens up the possibility that discussion may move beyond issues that were made ready for public consumption.

The study that follows addresses these criticisms by explicitly focusing on older people's perceptions of everyday experiences in a care home beyond the initial move and explores longer term living in that environment. By enabling residents to tell stories of their life over an extended period of time the voice of the older care home resident will become audible, and through the process of the telling what was previously invisible will be made visible. In this way the study will make a unique contribution to the growing body of care home literature.

Chapter 3

Seeking ways to understand: Philosophical foundation, method and design of the study

Introduction

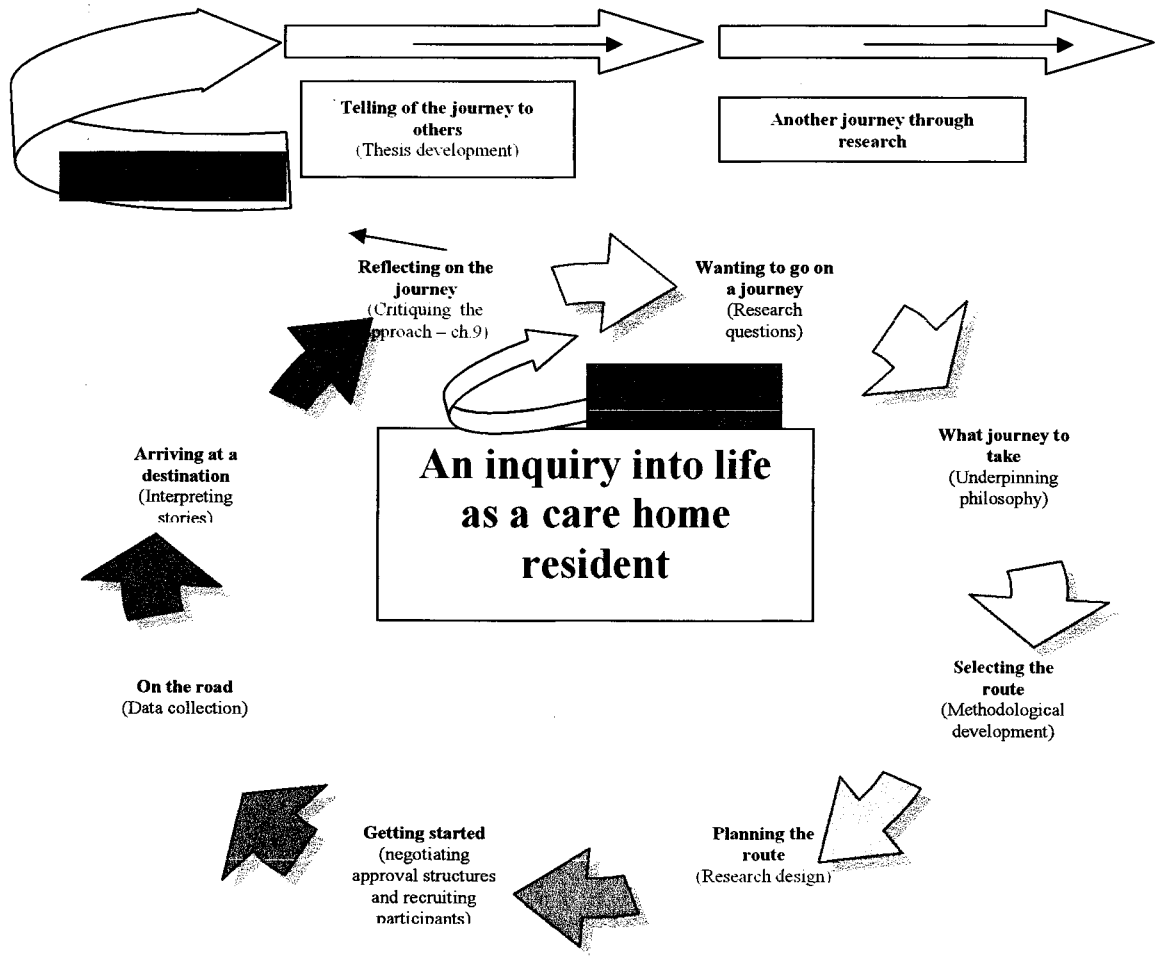
Knowledge and understanding of older peoples' experience of living in care homes is developing, however the discussion in the previous chapter pointed to some of the gaps that persist. My curiosity motivated me to focus this inquiry in the pursuit of advancing knowledge in one of these areas, whilst furthering my understanding of the research process. Consequently, this was a voyage of personal discovery where the process of working my way through research philosophy and methodology was as important as the outcome of the inquiry. As I journeyed through the various stages of the research process I became more aware of the need to be reflexive in my stance, an approach promoted by Mezirow (1990), and to adopt this in my practice.

In keeping with this, the account that follows is a description and a reflection on the research journey that I have undertaken. Thus, it is a story within the wider story of the thesis itself. Throughout the presentation of the research process I draw on the research texts that influenced methodological decisions, and examples from the resident interviews (from this point on the following pseudonyms are used to refer to the participants - Anne, Beatrice, Charles, Doris, Edna, Florence, Gloria and Harriet) to explain the research process. Particular attention is paid to the decisions, issues and challenges that arose throughout. Koch (1994) referred to this form of reporting as providing a *'decision trail'* for the reader. By doing this the researcher imparts more than mere facts, the rich description of key events and decisions are presented to enable the reader to discover the researcher's standpoint and how I reached my interpretation of the data. By engaging with what Schon (1983) described as the messiness of practice, in this case research practice,

the reader is then positioned to share the researcher's understanding that was achieved through the research process.

The metaphor of a journey is used to give a structure to this chapter that incorporates details of all aspects of the study. The various stages along this journey are presented in figure 3.1 in an attempt to give the reader a cognitive map of the research process that is now presented. The account of this journey attempts to reflect the qualitatively different activities that occurred along the way by embracing descriptive and discursive styles of reporting. An alternative way of giving an account of the research process would have been to present a chapter reporting on the philosophical underpinnings of the study, followed by a separate methodology chapter. This was rejected as it pointed

Figure 3.1: Journey through the research process



to separateness rather than demonstrating consistency in the study's ontology (nature of reality), epistemology (relationship between researcher and participants) and methodology (how knowledge is gained).

Wanting to go on a journey (Research questions and aims)

The focus of this study emerged from many separate situations that I had experienced in care homes, as outlined in chapter 1. These situations drew my attention to the lack of understanding of what it is like to live in a care home for 24 hours per day, 7 days a week, year on year. As a nurse, and later as a nurse tutor and then as a researcher my interest in developing an understanding of the experiences and views of care home residents grew, providing the focus for this inquiry.

As noted at the summary of the preceding chapter, the bibliographic overview confirmed the relevance of the focus of the study to contemporary long-term care of older people in the UK. This overview highlighted the dearth of literature that portrayed the older person's perspective of living in a care home. Whilst there is a powerful negative image of older residents as passive recipients of the regime of a care home within the literature on institutions, there is an emerging literature, since the 1990's, that points to frail older people as active participants in shaping their lives in care homes. In Reed and Roskell Paytons' (1996) study (discussed in chapter 2, p.33) the researchers concluded that older people made active adjustments to their life throughout the transition to a care home:

> 'residents are frequently active and interested in the community dynamics of the home in a way that challenges the stereotypical images of passivity in these homes' (p.81).

Whilst these ideas have been discussed in further detail in chapter 2, the important point to be made here is that this emerging literature highlighted the way that older people were socially active and not necessarily passive beings, tossed and turned by the institutional processes and structures of a care

home. These ideas strengthened my desire to seek an understanding of a resident's life and how they shaped that life, from their perspective. As we saw in chapter 2 there are accounts of the staff's view of the way that residents shape their world (see the discussion of Debra Paternity's work, p. 34), yet there is a lacuna in the research literature regarding the residents' understanding of this. As my ideas developed they shaped the following research questions:

- How do older people describe their daily lives in a care home?
- What factors influence and shape their experience?
- To what extent do older people shape their own lives in a care home?
- How would older people want to live in a care home?

My personal experience had now moved from curiosity and general interest to beginning a journey of inquiry. At this point the following aims were constructed to set the direction and parameters for this voyage of discovery:

- to investigate older people's experiences of living in care homes in England
- to explore the dynamics which shape this experience
- to develop a model that draws attention to older people's participation in the shaping of their lives in the care home.

What journey to take in this study (Underpinning philosophy)

There are many different ways to examine social phenomena, hence a decision had to be made about the most appropriate basis for this research. Whilst much has been written about life and work in care homes, in the context of the research literature the voice of residents is overshadowed by many other voices including that of researchers and care staff. As a consequence, less is known about the older person's understanding of their life as a resident in an environment that is largely on the periphery of

mainstream society. The research required an approach that elicits accounts of experiences of those who live in care homes. Though people may articulate the understandings that they hold of their experiences in a care home through language, the inherent difficulty in sharing those understandings with another person is that the giver and receiver may not share the same understandings of the words that are used to give expression to that experience. This suggests that there is no objective relationship between words and the social world that people experience – words are merely symbols and signs that people use to portray their inner experiences to others.

It is through a process of interpreting those symbols and signs that understanding is possible. One way to do this is through conversation, where individuals exchange words until they reach an agreement that they have achieved an understanding of the views of the other person. The exchange of words is an act of interpretation in itself, and the very process may do more than lead to understanding. The process may result in new understandings or new meanings being attached to the experience that the person is attempting to express. Understanding is therefore continually evolving. By capturing what the participants say about their experiences, and entering into conversation about the meanings that are embedded in those experiences, interpretation provides a way of moving beyond the text to reveal inner experiences. This is consistent with hermeneutics, the theory and practice of interpretation.

Hermeneutics: the science of interpretation

Within the discipline of hermeneutics diverse approaches have emerged to enable theologians, jurists, philologists and researchers to access the possible meaning of texts and the inner world that people live in. Although the origin of hermeneutics can be traced back to Ancient Greece (Platonic or dialogical hermeneutics) and through to the biblical exegenesis period, it was not until the 17th Century that the discipline of general hermeneutics came into being (Grondin, 1994). Philosophers of the enlightenment proposed that hermeneutics rested on certain generally applicable rules and principles,

which were valid for all those fields of knowledge that relied on interpretation. The general understanding of hermeneutics, however, has changed throughout time and now is generally considered to be a theory concerned with understanding phenomena by bridging the gap between the researcher's personal context of understanding and that of the researched (Palmer, 1969; Reeder, 1998; Benner, 1994; McCormack, 1998).

The general system of hermeneutics is most closely associated with the work of Friedrich Schleiermacher (1768 - 1834) and Wilhelm Dilthey (1833 - 1911). Modern hermeneutics is most closely associated with the works of Martin Heidegger (1889 - 1976) and Hans-Georg Gadamer (1900 - present). Each of these philosophers made a significant contribution to the development of this philosophical tradition by advancing the scope of hermeneutics and its methods. It is not possible to discuss the extensive works of these philosophers within this thesis, therefore the discussion will be restricted to those aspects of their work that have had a major impact on the shape of this study.

Central issues for designing and conducting this inquiry

When embarking on this investigation I set out to understand the meaning that older people attributed to their lives as residents in care homes. As a nurse I had assumed that I understood certain aspects of this experience, yet as my knowledge developed, first through my practice and later through examining texts concerning this subject, I questioned the understandings that I had acquired of care home life. This led me to consider whether this was the experience of others, and indeed the nature of all experience - that it was constantly changing as soon as it was realized.

It was only through reading and reflecting on some of the metaphysical arguments contained in the texts written by Martin Heidegger, Hans-Georg Gadamer and Paul Ricoeur, for example, that the relevance of my experiential discovery became evident (Heidegger, 1962; Gadamer, 1975, 1976,1989;

Ricoeur, 1976,1991). In my attempt to understand the experiences of older people living in care homes, I needed to develop a framework that enabled them to give expression to their experiences within the context of their life. Their speech and their actions had the potential to signify the meaning of their experiences. But I had also become aware that the process of telling led not only the researcher but the researched to enter into a process of interpretation to discover the meaning of the experiences that were discussed. Moreover, the process of interpretation could never lead to the truth - it was merely an interpretation, but that interpretation could be complete in itself.

The hermeneutic process according to Gadamer is a dialogical process. In this a dialogue is created between the interpreter's and the researched's understanding of a particular phenomena and in this way one of the main problems of interpretative social science is addressed - that of restricting the explanation of action to the actor's concepts. Gadamer describes the process of coming together as a *'fusion of horizons'* - the horizon being an individual's range of vision that includes everything that can be seen from a particular vantage point as highlighted in the following text:

> 'The same is true of a conversation that we have with someone simply in order to get to know him, i.e. to discover his standpoint and his horizon. This is not a true conversation in the sense that we are not seeking agreement concerning an object, but the specific contents of the conversation are only a means to get to know the horizon of the other person' (from Muller-Vollmer, 1985: Gadamer p. 270).

Gadamer's hermeneutics does, however, open up the possibility that different interpretative outcomes can arise when the interpretation of language is the vehicle for exploring experience. Ricoeur (as edited and translated by Thompson,1981a) argues that language, by its very nature, can convey at any point in time multiple meanings that are only understood through a process of interpretation. Dialogue, therefore, is a precondition to understanding, but a precondition that can result in more than one outcome. Ricoeur develops this notion in the following passage:

> 'this finitude does not enclose me in one point of view. Whenever there is a situation, there is a horizon which can be contracted or enlarged.

> We owe to Gadamer this very fruitful idea that communication at a distance between two differently situated consciousnesses occurs by means of their fusion of horizons, that is the intersection of their views on the distant and the open. Once again, an element of distanciation within the near, the far and the open is presupposed. This concept signifies that we live neither within closed horizons, nor within one horizon' (From Thompson, 1981: Ricoeur p.62).

As I embarked on this study I held my own understandings of life in a care home and so did the older people. Within the method, therefore, opportunities for the telling of events in the lives of the participants and for dialogue between the researcher and the researched were essential. In this study, dialogue had to become an active process whereby the researcher and the researched discovered each other's standpoint and through their interaction a shared understanding of living in care homes could develop.

Developing a shared understanding, therefore, was an issue that loomed large in the study. It was all too easy to make the assumption that words and expressions have a common meaning that is shared between those involved in a conversation. The research approach, therefore, adopted a framework that enabled the researcher and the informant to enter into dialogue with each other and constantly check out that they indeed held the same understanding of an issue. This was built into the methodological framework as described later in this chapter.

Within hermeneutics, as framed by Gadamer and Ricoeur, the personal experiences of a researcher are not considered to be an impediment to the researcher's ability to understand. This is in contrast to the position taken by other philosophers (see for example, Husserl, 1962; and Merleau-Ponty, 1968) who believe the way to eradicate prejudice is to maintain objectivity by not considering previous experiences or by bracketing pre-understandings. Gadamer (1975) reinforced this viewpoint when he stated:

> 'To try and eliminate one's own concepts in interpretation is not only impossible, but absurd. To interpret means precisely to use one's own preconceptions so that the meaning of the text can really be made to speak for us' (p. 358).

These tenets were built into the research framework to enable the researcher to declare her background and pre-understandings of life and work in care homes as set out in chapter 1 (rather than pretending that these did not exist, or bracket and set-aside these understandings as in some research traditions). Equally important to the inquiry was developing a framework that allowed the participants to speak of the events that shaped their lives with no interference.

As the research progressed, interaction between the researcher's and the older persons' perspectives about living in care homes was a necessary condition to move toward a '*fusion*' of individual horizons. This was facilitated by revisiting the participants' accounts of daily experiences and by examining the interpretations that were made of those experiences at multiple stages throughout the study. This created a movement between the part and the whole. The continual interaction that resulted between the researcher and researched evolved into what is known as a '*hermeneutic circle*' where the aim is not to understand better but differently, viewing all interpretations as complete in themselves but never ending, as interpretations of interpretations lead onto new understandings. When analysing data the researcher undertakes analysis at two levels. First, interpreting individual data sets for particular meanings; and secondly integrating data sets into a whole picture and understanding the meaning of the picture that is created.

It has been argued here that understanding emerges from interpretations, which change and develop throughout the research process. Opportunities for the researcher and researched to meet and discuss the same events and subjects as understandings developed were essential. In theory this was achievable, but in practice this was difficult. Being able to meet with the same older people over a period of time that extended beyond six years was considered to be unlikely. Care home residents are frail and their physical and mental condition is changeable. In acknowledgement of this it was planned at the outset of the study to meet with the participant regularly (two weekly meetings at a minimum) and at the point of completing interviews with them

(approximately four months on from the first meeting) to seek a shared understanding of their experiences.

In the research process, the task of understanding is to show how the fusion occurred between the worldview of the researcher and the researched. Koch (1996) suggests that this may be achieved through the reporting of research, by demonstrating how the researcher participated in making data, depicting the voice of the participant, giving insight to the social and historical context of the research, and by showing how the horizons of the interpreter and the interpreted are fused. For the reasons discussed above, this thesis is more than a written record of the events that took place during the various stages of the research process. It is an ongoing dialogue that takes its place alongside other discussions of this topic to develop new insights and advance understanding of life in care homes as perceived by older people that live in that environment. Nevertheless it has boundaries, not least in time and place.

Selecting the route (Methodological development)

In deciding that the research questions demanded an interpretative methodology informed by Gadamer's ontological hermeneutics and Ricoeur's writings on interpretation, the overarching framework for the study had been established. Within this approach came tenets that determined how the researcher should approach and interact with the data. However, I needed to consider the most appropriate methods for collecting data. This study had the very ordinary, everyday experience of living in a care home as its focus. Therefore, the design of the methods needed to develop a way of accessing this experience and provide a basis for interaction between the researcher and the participants.

Rarely do people stop and consider the value that they attach to their circumstances and only occasionally do people reflect on the factors that shape their daily experiences. People do, however, engage in a process whereby they story their lives. They tell of actual life events and the

happenings that take place everyday in a way that Bruner (1995) suggests is a representation of reality rather than accurate retelling or recording of events. During my interaction with older people I had often observed the ease with which they told stories of their daily lives and the way that they readily reflected on the feelings, sentiments, images, desires and thoughts that were associated with the story being told when they were given the personal space to enter into such a dialogue.

My prima facie judgement at this stage of the study was that an approach that used the familiar (stories of everyday occurrences) to seek the unfamiliar (the meaning that older people attributed to their lives as a resident in a care home) would be acceptable to older people and it would enable the interpretation to move from a description of events and actions to a search for the embedded meaning of that experience. I turned to an exploration of biographical approaches and subsequently to narrative methods to inform the study with the aim of maintaining consistency between the philosophy underpinning the study, the research approach and the method.

An interpretative study informed by a biographical approach and narrative method

Biographical research is part of the broader practice of qualitative methods that uses the stories people tell about their circumstances, and other personal materials to understand the individual life within its social context. In the field of gerontology, biographical approaches have become increasingly used as a method to reveal how ageing is experienced and how people theorize about the changes that take place as they age. For example, Bornat et al (1998) explored the impact of family change on the lives of older people. The team used a life history method in interviewing and they found that the participants were able to reflect on their lives during the interview and to develop their own understanding to describe the experiences of family breakdown and reconstitution. In practice biographical approaches are also being used by practitioners and valued by older people as a way of having personal

biographies recognized as a basis for individualized care (see for example, Nolan, 2000, Clark, Hanson and Ross, 2003).

Denzin (1989) has argued that a complex family of research methods exists within the biographical approach and the scope of biographical research has expanded. It now includes life history work, case history, narrative, case study and discourse study among other methods. A key decision in the present study was the selection of a method that facilitated access to older peoples' current experience within their life course. The literature, for example Nolan et al (1996) and Oldman and Quilgars (1999), suggests that experiences prior to and following the move to a care home have the potential to impact on an individual's perception of their current situation. It was therefore important that the method adopted in the study facilitated access to all aspects of the participant's life with a particular emphasis on their current life in the care home. It was anticipated that this could be achieved by combining life story and narrative methods in research design.

Further deliberation of the method for the study was undertaken by a review of the wealth of literature that exists on biographical approaches. Many issues were identified and these guided decisions in the development of the design of the study. The following subjects had a particularly profound influence on the shape of the study and are discussed in greater detail in the following section of the thesis:

- *Telling and retelling the story* - creating personal space where participants are able to tell their personal stories of life in a care home
- *Emerging narratives* - remaining sensitive to emerging narratives as understanding develops through the process of telling and retelling stories
- *Multiple narratives* - capturing diverse views about life in the communal environment of a care home
- *Privileging the views of older people* - ensuring that the understandings of the participants are emphasised at all stages of the research, and
- *Establishing and maintaining dialogue in the research approach.*

Key issues that shaped the research design in this study

Telling and retelling the story

In the field of gerontology narration has been used as a data collection method as it enables older people to give their accounts of their life, it's events and related happenings through storytelling. Various authors suggest that there are two dimensions to storytelling - the chronological dimension whereby events are discussed as a sequence of episodes, and the non-chronological which involves the construction of a whole from successive events or the configuration of the plot (see for example, Plummer 1997; Flick 1998). Jovchelovitch and Bauer (2000) argue that the plot is the essential component of a narrative structure. They state:

> 'It is through the plot that the individual units (or smaller story within the big story) in the narrative acquire meaning. Therefore a narrative is not just a listing of events, but an attempt to link them both in time and in meaning. If we consider the events in isolation they appear to us as simple propositions that describe independent happenings. But if they are composed into a story, the ways in which they are related allow for the meaning-production operation of the plot. It is the plot that gives coherence and meaning to the narrative as well as providing the context in which we understand each of the events, actors, descriptions, goals, morals and relationships that usually form a story' (p.59).

What is included and what is missed out of a story is shaped by the plot. It determines the beginning and the end of a story, which does not exist in such a precise manner in social life. Through the structure of the research design the researcher elicits the participant's stories and through the process of telling the plot is disclosed.

Chamberlayne, Bornat and Wengraf (2000) reiterated the value of narration as a method that had the potential to access rich descriptions of the participant's experiences. They also argued that narration had a social function that researchers ought to be aware of when planning their studies and to exercise caution to develop strategies that facilitate the telling of stories that move beyond those that the participant assumed the researcher was seeking:

> 'life story, as told, may be a product of a life made ready for public consumption in a situation where identity is at risk from the negative stereotypes of frailty and the processes and procedures of caring' (p.10).

This statement provides a strong warning to researchers who are working with older people who have moved to a care home. These people live with the impact of stereotypes of frailty and being a recipient of care, and the influence of this should not be easily dismissed. By the time that an older person has moved to a care home it is possible that they had been exposed to situations where they were marginalised from decisions that affected their life and their views ignored (Sandberg, Lundh and Nolan, 2001; Reed et al,2003).

Previous experiences, both positive and negative, have the potential to shape the dialogue and the interaction in this study. Approaches to data collection, therefore, required sensitivity from the researcher to encourage the participant to move beyond the public stories that they told and tell of their private inner world - their joys, struggles and reactions to life in the home. Also, attention needed to be given to develop a research design that facilitated the building of a relationship between the researcher and the participants and to the retelling of stories rather than recalling actual stories that were ordered according to a specific chronological sequence.

On the basis of the factors discussed above, the decision was made to invite the participant to take part in a sequence of interviews that would take place approximately every two weeks, but the actual scheduling of the interviews would be determined by the participant.

Emerging narratives

Situational factors also play a decisive role in the construction of narratives. In this study the participants were invited to tell their stories, and as they did this they had the opportunity to reflect on the events that they were recalling. This opened up the possibility that new meanings could be established as they discussed their experiences. The design had to be sensitive to capture such changes.

Multiple narratives

The way that situations and the context of the research influence the construction of narratives has been reported in the wider literature. For example Biggs et al (2000) found, in their investigation of cultural narrative in a purpose built retirement community, that there were individual stories and shared narratives that were based on a common experience or community identity. They concluded that the shared stories were used as a general means to sustain well being and construct individual identities in this living arrangement through association with a larger, collective narrative. Three narrative forms were identified in their work:

- formalised statements about the aims, objectives and lifestyle pertaining to the retirement community project (formal documents/literature)
- descriptions of events as experienced by the tenants (Retirement Community as experienced by the tenants)
- stories and images which encapsulated the community as it existed in the imagination (Retirement Community glimpsed through metaphors used by tenants – positive futures, miracle cures).

The way that situational factors contribute to the creation of stories and narratives highlights the importance of eliciting different stories by different individuals at different points in time to capture diverse views about events and the daily occurrences in care homes.

Privileging the views of older people

In many situations research participants select the information that they want to impart to researchers. This was a challenge that I had to address in order to examine the world through the participants' eyes. This factor affirmed my decision to adopt a narrative method during data collection as this approach has been purported as privileging the informant's perspective and keeping the influence of the researcher to a minimum (Schutze, 1977).

A particularly challenging aspect of this study was developing and maintaining dialogue between the researcher and the participants as the study

progressed. It was anticipated that this could only be achieved to a limited extent. It was likely that the age and frailty of the participants would reduce the possibility of maintaining continual engagement with them throughout the entire study. As a way of addressing this, the research design needed to provide opportunities for sharing ideas and developing interpretations throughout. This pointed to the need to establish regular contact with the participants for an extended period of time during which they would be actively involved in the interpretative process (as described in chapter 4). At the end of this time the final interview would provide an opportunity to revisit, review and revise the themes that had been developed throughout. This strategy was not only feasible and practical, it was necessary so that a '*meeting of understanding*' could be achieved.

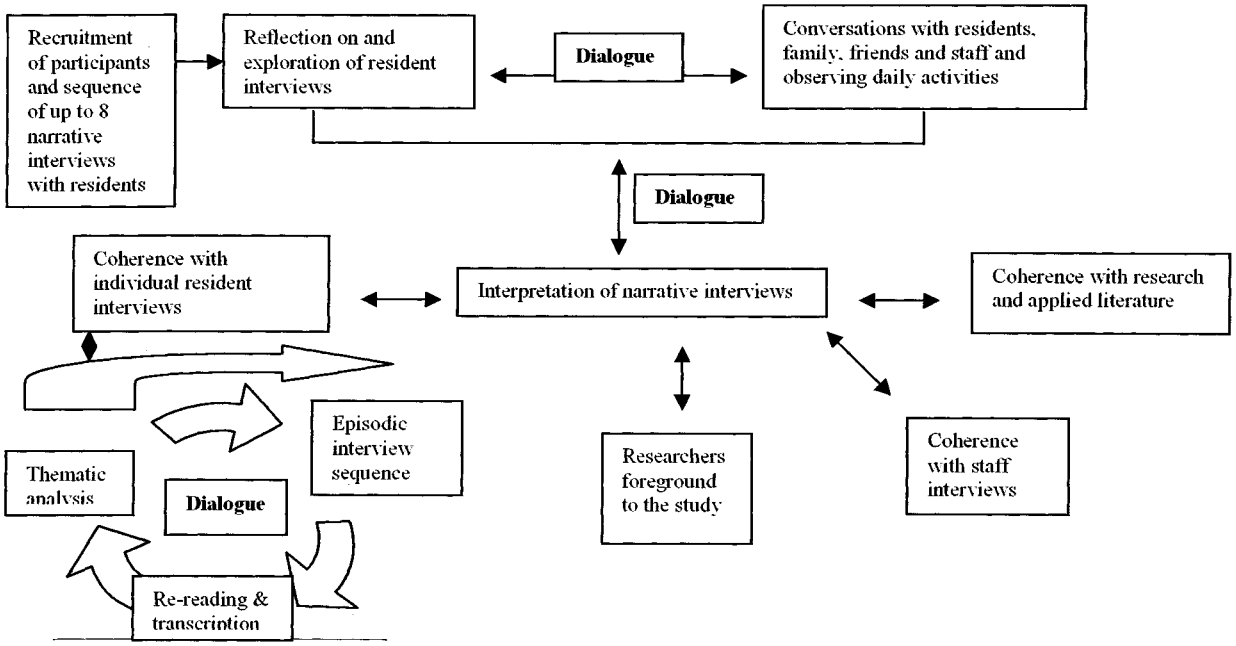
Establishing and maintaining dialogue in the research approach

From the beginning of the study I was aware that my engagement with the research and applied literature was challenging and changing my understanding of life in a care home and how this could be explored in this social situation. In other words, I was entering into a dialogue between my reading, in parallel to other processes that were taking place, and myself, and this was shaping the study as a whole. In recognition of this I sought to develop a methodological framework that facilitated dialogue between the multiple levels and layers of data collection and data analysis as the study progressed rather than solely during the process of interpretation. In doing this I was developing a hermeneutic circle throughout the research.

The development of reflexivity and movement from description to interpretation was also supported by the decision to establish prolonged and regular interaction between the researcher and the participants that, in turn, introduced a strategy within the design for confirming or refuting the findings with the participants. Lincoln and Guba (1985) highlighted the importance of establishing the credibility of an interpretation by returning to the participants to see if they recognize the findings as true of their experience, and in doing

so this process supports the rigour in a study. Guba and Lincoln (1989) argued that credibility is enhanced when the researcher becomes familiar with the culture being studied through prolonged engagement with the field. This was achieved by maintaining contact with an individual resident for approximately six months through a series of interviews as discussed in the following section of this chapter. Through repeated visits to the same care home the researcher learned about the culture in the home and built up trust with the participants. Prolonged engagement also enabled persistent observation of life in a care home, which facilitated greater depth of understanding. In the following diagram the methodological framework for the study is depicted. It has been produced to illustrate the multifaceted, yet integrated, nature of the research.

Figure 3.2: Methodological framework



Planning the route (Research design)

Through the review of the methodological literature, decisions were made that led to the development of the overarching methodological framework. This was consistent with the overarching aims of the study, but I remained aware of the importance of carefully planning the research design to facilitate access

to the experiential world of care home residents. This design had to create a context where frail older people felt safe to tell their stories, and were encouraged to tell their story and not the story that they anticipated that the researcher wanted to hear.

Schutze (1977) and Flick (1998), amongst others, point to narrative methods as a way of accessing the voice of marginalised populations and promote the notion that narrative interviewing techniques elicit rich accounts of experiences in a more comprehensive way than traditional approaches to interviewing. Schutze first suggested systematization of the narrative interviewing technique in 1977 following a study on local power structures and decision making processes. Since that time the framework has been adopted by researchers working within the field of biographical research and adapted to their work. It consists of a number of phases – preparation for the interview, initiating the interview, the main narration, a questioning phase and the concluding discussion where the informant can be asked questions that attempt to ascertain theoretical accounts of what happened and the meaning attributed to the events.

The preparation and the initial part of the interview are vitally important as this stage influences the remainder of the interview. For the participants in this study this was a new experience and for some it was a time when they experienced uncertainty about what was expected of them, although they had been fully informed of the nature of the study and had given their consent to take part. Some were unsure where to begin and what to tell when given the opportunity to speak of their experiences, as is illustrated from the following extracts:

> *"Well my life is not very interesting and I don't know where to start."*
>
> (Anne: interview 1)

> *"But what have I got to talk about....I will take some starting I will tell you."*
>
> (Charles: interview 1)

The participants required encouragement to talk of their lives and share stories of their experiences. Prompts such as "*I am sure that you have*

something that you would like to talk about," or focusing their attention on their life story by stating "*would you tell me about your life,"* or asking an exploratory question based on their opening statements quickly moved the initial interview on from introductory statements to a rich description of their history, encounters, preferences and aspirations.

During the main narration the researcher is concerned with, first, prompting the informant to tell their story about a significant event in their life and social context and, during the narration, maintaining its flow. As the participant moves in and out of narrative flow, the point in the narration where they tell vivid stories of episodes in their lives, giving expression to the emotions that they experienced, the researcher uses active listening and non-verbal prompts to encourage the participant to continue their storytelling. In the following extract from Anne's second interview she tells of a time when two residents, who were boarding in her care home for a short while following a fire in their home, wandered uninvited into her room:

> *"There were two of them, they must have been friends and they used to come walking hand in hand. Straight in here (her room) no bother, they would never speak, just walked over there and stare, a horrible stare, and that is all I could see of them. And they kept coming in and out so [the manager] decided to put a gate up. So it went up by the handyman and I thought that's lovely I would be able to sleep, because they would come in at night and all times. But it made me a prisoner and not them. I couldn't get the wheelchair through the gate because the opening was in the middle.....Well they came in the night and rattled the gate until it came off and they threw it onto the floor.....I had these two pillows on the floor at the time. They got hold of one of those and then they started banging on my feet with them."*
> Researcher: *"Oh no."*
> *"That's when I woke up and there they were at the bottom of the bed. I gave such a yell and the nurses came running. They nearly died when they saw the gate on the floor. But that went on for a few weeks until they found a more suitable place for them to stay. And then we had another lady....."*
>
> (Anne: interview 2)

In this illustration the informant tells a vivid story of this event and describes the emotion that she experienced. She was animated when she spoke and she used a lot of non-verbal gestures to amplify the event, such as pointing to the place in the room where the other residents stood and banging her hand

on the bed to stress the force that they had used. At the point where she stated *"banging on my feet with them"* she ceased talking and my response was adequate to indicate that I was actively listening to her and to encourage her to continue.

This form of interviewing is guided by rules that shape the interaction between the researcher and the informant to ensure that the inquiry centres on the informant's issues. Here the emphasis is on the way that language is used during an interview to ensure that it is familiar to and directed by the participant. During the interviews with residents this was particularly important because the language that I used could have portrayed an academic or professional world view and if this was used it had the potential to shape the interaction in a way that did not privilege the world view of the informant. Consequently, I attempted to use language that mirrored the words and phrases of the informant to maintain the flow of the discourse or words such as *'ah, ah'* or *'right'* to indicate that my attention was focused on what they were saying.

When I explored the literature about narrative approaches I was particularly influenced by Flick (1998) who questioned the appropriateness of narrative interviewing approaches as a way of exploring different forms of knowledge. He framed his argument in the following way:

> 'subjects' experiences of a certain domain are stored and remembered in forms of narrative-episodic and semantic knowledge. Whereas episodic knowledge is organized closer to experiences and linked to concrete situations and circumstances, semantic knowledge is based on assumptions and relations which are abstracted from these and generalized' (p.106).

In developing this argument Flick indicated that different approaches are required to access episodic (knowledge of direct experiences) and semantic knowledge (knowledge of concepts and ideas). Whilst narrative interviewing may access narrative-episodic knowledge, more direct forms of questioning are required to elicit semantic knowledge. In the technique known as episodic interviewing these approaches are combined and the informant is invited to

present narratives of situations, followed by discussion of the topics in the interview schedule. The approach, therefore, seeks to exploit the advantages of the narrative and semi-structured interview to enhance the scope of interviewing by progressively moving between episodic-situative forms of experiential knowledge and examination of specific concepts that relate to the focus of the investigation.

In a later analysis of the use of episodic interviewing Flick (1998) argued that it was appropriate when the aim of the investigation was to explore routines and normal, everyday phenomena. By examining the topics in the interview schedule over a number of interviews, the process is less tiring and less taxing for the informant. This is both desirable and appropriate for frail older people who may find lengthy interviews onerous. These factors influenced the decision to use this approach in this study.

Based on Flick's work, cited above, a sequence of interviews was developed (see table 3.1). These commenced with a life history interview. The subsequent interviews began with an invitation to give an account of their life

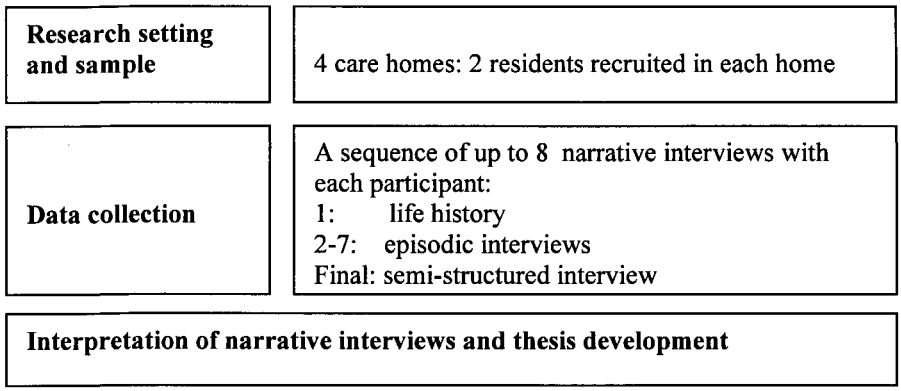
Interview 1: Tell me about yourself.
Interview 2
Opening remark: Tell me about what you have been doing since I last saw you.
Generative question: Tell me more about living with others in this care home.
Interview 3:
Opening remark: Tell me about what you have been doing since I last saw you
Generative question: When we met previously you mentioned (e.g. how you wait for others to be seen to by staff / changes you would like to see in this home).
Tell me more about these experiences.
Interview 4:
Opening remark: Tell me about your life since I last saw you.
Generative question: There are times when we feel more or less comfortable in the environment we live in.
Tell me about times when you felt more comfortable living in this home.
Tell me about times when you felt less comfortable living in this home.
Interview 5:
Opening remark: Tell me about your life since I last saw you.
Generative question: What are your views of living in the care home?
Interview 6:
Opening remark: Tell me about your life since I last saw you.
Generative question: In what situations do you seek contact with others in the home?
In what situations do you avoid contact with others in the home?
Interview 7:
Opening remark: Tell me about your life since I last saw you.
Generative question: What was missing from the interviews that could have given you the opportunity to tell me about your experiences of living in this home? What was missing from the interviews that could have given you the opportunity to tell me about the ways you influence your living arrangements in this home?
What was missing from the interviews that could have given you the opportunity to tell me about situations where you negotiate your preferences and care with other residents?
What was missing from the interviews that could have given you the opportunity to tell me about situations where you negotiate your preferences and care with other staff?
Interview 8:
Opening remark: Tell me about your life since I last saw you.
Generative question: Discuss the narratives identified from the initial analysis of the previous interviews in the sequence.

Table 3.1: Interview schedule

since the previous interview and then the focus turned to a specific issue about living in a care home that was identified from the literature and introduced to the informant through a generative statement or question. When the participant indicated that they had completed their discussion of the topic that was introduced to them, each interview moved onto a phase of narrative inquiry where the interviewee was asked questions that aimed to elicit theoretical accounts of what happened. This process, represented diagrammatically in figure 3.3, was replicated with each participant who lived in 4 different care home settings.

My earlier analysis of the philosophy underpinning this study highlighted the importance of ongoing dialogue between the researcher and the researched in the pursuit of developing a shared understanding. Through the phase of

Figure 3.3: The research design



narrative inquiry in each interview there was the opportunity for this and this was enhanced in the following ways. First, following each interview, and prior to the next interview, I transcribed the audio-recording of the interview. This provided an opportunity to listen and re-listen to the stories that were told. Each interview was then analyzed (discussed briefly in a later section of this chapter, p.81, and in detail in chapter 4) and stories, key issues and topics were identified and then entered into a schedule for the final interview in the sequence. The final interview was a structured discussion about the dominant narratives that had been identified during open coding of the previous

interviews in the sequence to seek clarification, amplification and affirmation. In this way there was on-going dialogue between the informant and researcher and continual development of understanding of the experience of living in a care home from the standpoint of the participants.

Getting started (Recruiting participants and negotiating approval structures)

Until now I have articulated the rationale for this study and discussed the underpinning philosophy and methodology to engage the reader in the decisions made in designing this study. The following discussion moves onto describing the research activity to give the reader a detailed account of what took place. This new phase began with examining the research field. This process informed decisions about the research setting, the selection of research sites and processes for identifying, selecting and recruiting participants. Throughout each of these activities there were a range of negotiations that were undertaken to secure the necessary approval to conduct the study and these are also discussed in detail in this section.

The research field

Developing an overview of the context of this study is fraught with difficulty. Information about care homes and residents is available from a range of sources, however comparing statistics is problematic because they are presented in different formats. It is generally agreed across different sources that the care home sector is diverse and it is constantly changing (Laing and Buisson, 2004, The Information Centre 2006). In the UK one of the most notable features of this change has been the transformation of care services from a predominantly public sector activity in the mid-1970s to a predominantly private sector activity now. Within the private sector there are major for-profit and not-for profit provider companies as well as the small proprietors - Laing and Buisson (2003) classify providers with more than 500 registered care beds as major care organisations. Though it is difficult to obtain accurate statistics regarding the total number of care homes, due to

constant opening and closure of providers, Laing Buisson (2003) reported that there were 29,890 registered homes in 2003 to provide services for approximately half a million residents across different client groups including elderly, physically disabled, elderly mentally ill, learning disabled and alcohol and those with drug dependency. Most (71%) of these homes, in England, offer residential and nursing care only, and the independent sector is the main provider of 90% of these homes (Goodman and Woolley, 2004).

Care homes exist in different forms – some are large private adapted dwellings and others are purpose built new establishments. They have different types of staffing arrangements that reflect the specification of the services provided by the home. Those homes, for example, that provide nursing care placements will have nurses as well as social care staff in the workforce. Some aspects of staffing, however, are less determined by care specification than a reflection of the philosophy of care underpinning service provision. This is illustrated in those situations where an activities co-ordinator is employed to facilitate a robust activities program rather than this being a further role that is undertaken by care staff. As well as variation in the type of services provided in care homes, the approach to delivery of these services also differs. In chapter 2, p 28 – 30, attention was drawn to the emphasis that has been placed on developing home-like or domestic-like environments in care homes and more recently to the creation of community within care home. It was highlighted here that different types of communities exist within UK care homes - some with a tendency to focus on the efficient delivery of care through routinised practices, whereas other homes focus on providing intimate and relationship-orientated long-term care.

Given this diversity it is highly likely that each care home is a unique social environment with its own culture. Examining older peoples' perceptions of their life in one care context may lead to understanding of the meaning of living in that particular context, however caution must be exercised in simply transferring that understanding from one context to another. This raises questions about the utility of research findings if the process of research only leads to understanding of social phenomena within a particular context that is

bound by place and time. Lincoln and Guba (1985), and later Meyer, Spilsbury and Prieto (1999) have argued in discussions about the generisability of qualitative research that transferability of knowledge and understanding is possible when the researcher gives a rich description of the context of the research in a way that enables the reader to make judgements about the relevance of the findings to a different situation.

The earlier discussion in this section goes someway to providing an overview of the research field; however a discussion about the resident population needs to be added to this for a more comprehensive overview. At 31 March 2006, 78% of the total care home population in England was aged 65 years and over. Hence, according to these statistics, 199,800 older adults were living in permanent and temporary placements in England (The Information Centre, 2006). Of this population 12% were aged 65-74 years, 35% were aged 75-84 and 53% were aged 85 or more, which is a similar distribution to that of 2002. The average age of female residents (85.6 years) being older than their male counterparts (83.2 years) (Laing and Buisson, 2004). The majority of people, 57%, were registered as occupying a residential care bed. Though there has been much interest in the characteristics of the care home resident population little information is available about ethnicity. It is known that that 3.7% of the 65 and over population in the UK are from minority ethnic groups, with 97% of this population residing in England, and 45% living in Greater London (Royal Commission on Long Term Care, 1999). With current discussions about long term care for older people focusing on provision that addresses individual need, there is a need to develop knowledge about key demographic variables within the is population such as ethnicity, as this would highlight issues for consideration when planning services.

Further information about the local research context is given in each of the following sections and descriptions of the selected care homes and participating residents is given in chapter five. This has been provided to enable readers to make judgements about the fittingness of the research to their own circumstances. There are, however, limitations that ought to be placed on transferring the findings derived from this study to other settings.

The argument that care homes and residents are unique, places restrictions on generalisation on the basis of contextual similarity. Any applicant of the findings derived from this study should utilize other approaches such as analytic induction (Silverman, 1993) in reaching judgements about the utility to their circumstances.

Recruiting care homes as research settings

The sampling strategy specifically aimed to recruit four care homes that had diverse communal living arrangements. Four care homes enabled access to a rich source of data, whilst being logistically manageable within the scope of the inquiry. The decision to generate a theoretical sample was shaped by Strauss and Corbin's work (1990) where they argued that the sampling of events and incidents with certain categories, properties, and dimensions, could enable the researcher to develop theory and conceptually relate to the object of the investigation. To generate a theoretical sample, a systematic process of sampling described by Reed, Procter and Murray (1996) was used. In this process the full range of potential sampling units are identified and rules are devised to guide subsequent decisions about selection that reflect the theoretical concerns of the research. The sampling process that is described below commences with a rationale for convenience sample of the care home sector in North East England and moves onto give details about the generation of the theoretical sample.

For practical reasons a decision was made to locate the study in two localities in the North East of England to facilitate easy and frequent access for data collection. These areas served both lively cosmopolitan inner city areas and quiet suburban districts. In location A, 18% of the population was aged 65 and over with 21% in location B. The population in each locality was primarily white, and the evidence from the 1991 census supported this observation, with only 0.67% from black and ethnic minority groups. It is anticipated, however, by the Quality of Life Partnership, that the population would become more diverse in the future. Their conclusion was based on an analysis of

population statistics that indicated that this proportion of the population had increased to 2.2% in 2006 (Quality of Life Partnership, 2006).

The number of care homes varied in each site. In site A there were 52 residential, 12 nursing and 3 dual registered homes; in site B there were 44 residential, 12 nursing and 26 dual registered homes at the commencement of the study.

A letter of invitation to take part in the study was sent to 149 home managers and they were requested to complete a questionnaire if they were willing to participate. The questionnaire asked about the registration category, number of residents, proprietor arrangements, organization of care, the social activities program and type of living areas in the home as these were identified as key attributes of communal living environments from the literature review. The 16 responses were anonymised with an alphabet identifier and the questionnaire responses were entered into a sampling matrix (see table 3.2). By entering details of the homes into this grid a visual display of key care home characteristics was created. This display highlighted the range of homes in the potential sample and illustrated that all possible configurations for care homes were not available to sample.

Four homes were selected to ensure that the sample was diverse. The sample included one 20 bed nursing home, a 40 bed dual registered home, a 78 bed dual registered home and a 40 bed nursing/ residential, and high dependency elderly care home (further details of these homes are given in chapter 5, p.117, 130, 142 &156). Hence large and small homes were included. There majority of residents were female in these homes and there were no residents from black and ethnic communities. Only one of the homes had a designated activities co-ordinator.

Sampling matrix

149 care homes registered within 2 localities were sent a questionnaire to explore whether they would take part in the study and identify features of the home such as registration category, organisation affiliation (whether the home was part of a company, and the size of company), number of resident placements, organisation of care, social activities program and type of living areas in the home. Responses were obtained from 16 care homes The home were anonymised with the use of an alphabet identifier (a – q excluding 'o'). Details extracted from the questionnaire have been entered in the following table for each of these homes.

Care Homes selected for the study are highlighted in the table. These are homes: j, e, f and p

Registration category	Organisation No small large vlge <3 3-20 >20				No. of residents	Organisation of care 1 2 3 4				Social activities program 1 2 3			Living areas Public	Private
Nursing	g	m	**j**	c	c = 20 g = 20 **j** = 20 m = 60	c g **j**	m	g **j** m		m	**j** c g	g m	c **j** m	c **j** m
Nursing/ residential	d			**e** **f** i k l q	d= 40 **e** = 40 **f** = 78 i = 44 k – 35 l = 48 q = 44	d **e** **f** i k l q	**e** k l	d **f** q	**f**	d **f** l q	i k	**e** k l q	d **e** **f** i k l q	d **e** **f** i k l q
Nursing/ residential/ High dependency elderly care				**p**	**p = 40**	**p**					**p**		**p**	**p**
Nursing/ Elderly Mentally Infirm			a b	n	a = 40** b = 55 n = 17	a n	n			b n	a	a b	a b n	a b n
Elderly Mentally Infirm														
Nursing / Young Disabled Unit				h	h = 50					h			h	h

Key to codes

Organisation of care
1= key worker
2 = named nurse
3 = team
4 = primary nurse

Social activities program
1 = activities co-ordinator
2 = care staff
3 = manager/matron

** = 35 Elderly Mentally Infirm and 15 residential residents

Table 3.2: Sampling matrix

The sample - resident participants

Within each research site a public meeting was held to provide general information about the study and to give an open invitation to residents to participate. This approach ensured that all of the resident population were aware of the study and were given time to consider their involvement. As there was limited contact between the researcher and residents it also led to a non-coercive situation to enable individuals to make their decisions. Residents who indicated that they were interested in participating and met the following criteria were approached by the home manager and asked if they were willing to discuss this study in greater detail with a researcher:

Inclusion criteria:

- resident in the care home for more than six months
- aged 65 years and older
- able to give consent to participate in the study
- able to take part in lengthy discussion over a number of interviews.

This approach was agreed with the relevant NHS Local Research Ethics Committees (LREC) as it ensured that the older people were given the opportunity to consider their involvement or decline to do so. In each home two residents volunteered and an appointment was made to discuss the study and their potential involvement (n=8). Seven female and one male resident between the ages of 52 and 95 volunteered to take part in the study. They had resided in these homes between one and a half and six years (see table 5.1, p.114 &115).

The sample - care home staff

During the interviews with the residents they spoke of key workers who had contributed to their quality of life in the care home. These staff members (n=14) were approached and were invited to take part in the study (see table 3.4, p.81) to explore their views of providing care in a group living setting.

Seeking ethical and organisational approval to carry out the study

When the study commenced the processes for the governance of research in the care home sector were developing. Much of the practice that existed at this time built on the customs adopted in the Centre of Care of Older People at Northumbria University, which were based on Northumbria University policies and the Department of Health research governance framework (DoH, 2001d), such as respecting the rights of participants and ensuring that data was managed in ways that met the requirements of the Data Protection Act 1998. In addition to adhering to these practices, multiple forms of approval were negotiated prior to commencing data collection.

First, approval to conduct this study was obtained from the two NHS Local Research Ethics Committees (LREC) that served the localities that were to be included in the sample. This form of approval may not have been necessary in approaching some care homes, whereas it was required for those that were contracted by statutory health care organizations to provide care home placements for older people needing long-term care (see appendix 3). Even if this form of approval was not necessary, it was considered best practice when approaching care homes to take part in research. At the stage of recruiting care homes to participate in the study, identification of the status of the homes was difficult. Therefore, approval was sought to approach all the homes that fell within the boundaries of the study setting.

Gaining approval to carry out this research from LREC was not straightforward. Members of the committees argued that residents' families ought to be approached prior to any contact with older people in the selected care homes. This was based on the premise that residents are vulnerable people who require protection; therefore an invitation to participate in research ought to be considered first by kin rather the older person. The inclusion criteria for participation in this study, however, explicitly stated that potential participants would be able to make and take this decision. Although they were living in a care home their right to make this type of decision remained. To do this the older person required information about the study, time to make the

necessary judgements and an approach that equally enabled the individual to decline or agree to take part. The approach described in the previous section - 'Sample - resident participants' – was agreed with the committee (for further discussion of the issues and challenges of researching and complying with research governance frameworks in the UK see Reed, Cook and Cook, 2004).

When LREC approval was gained a series of negotiations took place with the matron/managers as these people were the gatekeepers to the research setting as well as the potential participants. A letter of invitation to take part in the study was sent to the matron/care home manager of all the homes in the study setting. For those homes that were selected, as described previously, and agreed to take part in the study the systems for approving and monitoring research that were adopted by the home or the provider company were completed.

The third stage of the approval process was less formal but equally important. In all of the selected homes public meetings with the residents and staff were held to discuss the study and answer questions. These meetings were lively informal events. At the end of every meeting residents agreed that the study could be conducted in their care home and they were invited to inform the matron/manager that they would be interested in finding out more about the study. In three homes two people volunteered to take part in the research and in the fourth three people volunteered. One of these residents had lived in care homes for 12 years and had had preserved rights of tenancy. He was 59 years old, and therefore did not meet the inclusion criteria.

As the structures and processes for research governance changed in the United Kingdom the study was reviewed to ensure that it complied with ongoing regulations.

Ethical issues considered during resident recruitment, consenting and data collection processes

From the outset it was intended to invite care home residents to take part in the study. Although the inclusion criteria included only those who had the capacity to give their consent, this did not diminish the responsibility of the researcher to recognise that this may change as a consequence of illness and frailty. To address this, informed consent was regarded as a process that was continuously negotiated and that supplemented the more conventional formal consenting process (Dewing, 2002). Process consent was one of continual renegotiations and was particularly appropriate in this study where there was reflexivity between data to be collected and data that had been collected, and where the participants may have wished to place limits on the information that they made available as research data.

The consent process began when the participants indicated that they would be interested in finding out more about the study. They were fully informed of the nature of the study and what would be required of them. It was made clear at this point that participation was voluntary and that they could withdraw at any stage (see appendix 1). Residents with sight impairment had the information leaflet read to them and any questions that were asked were answered. For those who used hearing aids, it was ensured that they were in working order and environmental noise was kept to a minimum when obtaining informed consent. Their consent was recorded, either in written or audio form (see appendix 2).

As a way of reviewing their agreement to continue to participate in the study, informed consent was revisited at the beginning of each interview or visit. This enabled the participants to make decisions about being involved in the study according to their wellbeing on the day. Visits were planned in negotiation with the participants to ensure that the interviews fitted in with their care and social schedules. This process ensured that the frailty of the participants was considered at all stages of the research, which was particularly important in a

study that was planned to span a period of four - six months in data collection with each individual.

Issues concerning anonymity and confidentiality were considered carefully throughout the study. The study involved a small sample and the type of methodology adopted enhanced the possibility that the sample could be identifiable therefore, this situation placed a greater duty on the researcher to develop approaches to anonymise. The approaches used to enhance anonymity were discussed with the participants. They were aware that their audio recordings were to be transcribed and at this stage would be given a numerical indicator. They were also told that any reference to them would be done through the use of a pseudonym. Similarly, the descriptions of the care home that they lived in would provide sufficient detail to be informative to a reader, but inadequate to lead to identification of the home.

Throughout the study the needs of the older people were prioritised over that of the research to optimise benefit and minimise the potential for harm. It would have been extremely informative, for example, to carry out data collection until the participants left the care home. Whilst this would have led to the generation of knowledge, it is likely that it would have been intrusive to those involved. In those situations where the participants made decisions about premature termination of the interview sequence they were upheld.

Careful consideration was also given to the approach and timing of feedback to the participants and to the staff working in the care homes. It was clear from very early stages of the research that staff could learn about the impact of the practices in care homes from the residents' stories. Some of these stories highlighted the negative and damaging effect of institutional life. This is not suggesting that staff wilfully engaged in practices that were harmful to residents (in which case the researcher would have been duty bound to act in the interests of the older person), but lack of insight and understanding of the resident experiences did result in degrading and negative outcomes. If feedback had been provided immediately following data collection in each home, confidentiality may have been breached and it is possible that the

residents would have become more vulnerable following exposure of their perceptions of their experiences. The staff may also have experienced negative emotions as they became aware of the effect of their practices. To address this, feedback presentations in the homes were delayed until data collection had been completed in a number of homes. At this point it was possible to both anonymise the stories and share key messages arising from the study.

The above discussion highlights the range of ethical issues that are inherent in undertaking research with care home residents. Research in this setting needs careful planning and ongoing review to ensure that the rights of residents are upheld and their interests take precedence over the imperatives of the research.

On the road (Data collection)

This phase of the research process was concerned with initiating and developing a dialogue between the researcher and those living and working in the four homes recruited to the study. I had planned to carry out the sequence of eight interviews at two week intervals. As a way of fitting this into a busy work-life in the University I had planned to make fortnightly appointments with the residents, which allowed time to transcribe and complete open-coding of the interviews prior to the following appointment. According to this schedule the work in each home should have taken 18 weeks, allowing for time at the beginning to make the necessary arrangements and time at the end to do something with the participant (i.e. take them to a restaurant) as a way of thanking them for taking part.

As data collection proceeded and the participants determined when the following interview would take place these plans went astray. Sometimes there were three/four week intervals prior to the following interview to fit in with the resident's social schedule or to follow an important event or to accommodate illness. This form of control was significant because it enabled

the participants to shape the interview process. For example, Anne did not want the interviews to cease prior to the visit from her son who lived abroad. So she decided that there would be a gap between the seventh and eight interview to ensure that she could include this event in the account of her life in the home. This was important to her.

Although the prime focus of my attention was on the residents who agreed to take part and the people that the residents indicated had a significant impact on their experience in the home, I also entered into many discussions with their fellow residents, their visitors and the care home staff. These were spontaneous discussions that took place as I entered the home or approached the research participant in the public areas of the home. During the data collection period I became a familiar figure in the homes and these unanticipated discussions contributed to my understanding of life in the homes, which enriched my understanding of the informants' perspective.

Data collected

This involved collating information about the care homes (e.g. brochures, resident newsletters, information leaflets, notes from resident meetings), maintaining a research diary to record observations made during visits to the homes and conducting interviews with residents and staff. As discussed in an earlier section of this chapter (establishing and maintaining dialogue in the research approach, p.60), this form of data collection was viewed as an integral feature of the methodological framework. Through observing the happenings in a care home during my visits and conducting interviews with residents and staff an understanding of the context where the research was undertaken developed. Analysis of this data led to the pen portraits of the 4 care homes in the study that are presented in chapter 5. Whilst these portraits included a description of the home's physical features and the services that were provided, they also importantly included a discussion of the social climate that existed within each home.

The central focus of data collection was the stories that older people told about their lives as care home residents. Collectively, the eight older people who took part in this study participated in 42 hours and 5 minutes of interviews (n= 53 interviews). Though they were all invited to take part in a sequence of eight interviews, they indicated the point when they felt that they had completed the story of their life in the care home. For some, the story was told in five interviews and others eight interviews. In a similar way the participants controlled the length of each interview. Some interviews were short, lasting only 10 minutes, whereas others lasted up to 70 minutes. Table 3.3 gives details of the number and length of each interview that was undertaken between February 2001 – July 2002, and the average and total interview time for each participant

Resident	1: Anne	2: Beatrice	3: Charles	4: Doris	5: Edna	6: Florence	7: Gloria	8: Harriet
Number and length of interviews	1 = 70 2 = 40 3 = 65 4 = 70 5 = 55 6 = 65 7 = 70 8 = 65	1 = 55 2 = 60 3 = 65 4 = 60 5 = 50 6 = 50 7 = 70 8 = 55	1 =55 2 = 50 3 =35 4 = 50 5 = 45	1 = 50 2 = 60 3 = 40 4 = 50 5 = 30 6 = 50	1 =50 2 = 35 3 = 45 4 = 50 5 = 30 6 = 50 7 = 50	1 = 15 2 = 60 3 = 20 4 = 20 5 = 10	1 = 35 2 = 30 3 = 35 4 = 20 5 = 40 6 = 35 7 = 50	1 = 45 2 = 25 3 = 20 4 = 50 5 = 20 6 = 45 7 = 35
Total interview time	8 hrs 20mins	7hrs 45mins	3hrs 50mins	4hrs 40mins	5hrs 10mins	2hrs 15mins	6hrs 5mins	4hrs
Average interview time	1 hr 3mins	58mins	46mins	47mins	44mins	27mins	52mins	34mins

Table 3.3: Number and length of resident interviews

During the resident interviews, members of care home staff were identified as being influential in their experience of living in the home. They were invited to take part in interviews (see table 3.4) that explored the following topics:

- providing care that met the needs of the individual resident
- the creation of a group living environment
- their views about a quality communal living environment, and
- their experiences of managing situations where conflicts and tensions arose in attempting to meet the needs of the individual residents and needs of others.

Care home	Staff participant	Length of interview	Total time for staff interviews in the care home
1	Matron	70mins	3hrs 10mins
	Matron	30 mins	
	Care assistant	20mins	
	2 Care assistants	70mins	
2	Matron	40mins	1hr 45mins
	Diversional therapist	30mins	
	2 Care staff	35mins	
3	Matron and care manager	1hr 15mins	1hr 55mins
	2 Care assistants	40mins	
4	Matron	45mins	45mins

Table 3.4: Summary of number and length of the interviews that were carried out with care home staff

Arriving at a destination (Interpreting stories)

Reaching the planned destination is a major accomplishment in any journey. It is a satisfying time if things have gone well or a time of relief when the arrival signifies that obstacles have been overcome. Arrival is another point in a journey where the activity changes once again. Decisions have been made prior to and along the journey about what to do when the destination is reached. However, it is at this stage that judgments are made about the appropriateness and the feasibility of executing those earlier plans. As well as reviewing and refining plans there is a great flurry of activity as exploration of the new territory commences.

As data collection progressed, I entered into a dialogue with the participants. Their initial interviews exposed their individual identities and highlighted the diverse backgrounds that these people had lived. The subsequent stories in the interview sequence portrayed their unique ways of living in a care home.

This realization challenged the preconceived ideas that I had held throughout my practice and research experience in care homes, and challenged me in my role as a researcher to see the person that existed behind the resident. As I listened to their individual stories (through the telling and during the process of transcription), and re-read those stories as the inquiry progressed, I became increasingly aware that I was developing layers of understanding of the lives of these people. I witnessed their experiences as individuals, as members of the resident community in the care home, as people interacting with care home staff and as people relating to family and friends.

Being confronted with the wealth of detail that was being elicited through the data collection process was overwhelming and confusing. Each layer was distinct, bringing a different light to bear on the nature of care home life as it was experienced by eight different people. As each facet of the various layers was highlighted, this in turn shed a new light on what had already been revealed.

Data interpretation and analysis

Returning to the writings of Ricoeur (1991 & as edited and translated by Thompson, 1981a,) at this stage of the inquiry was particularly enlightening. The movement that I had been experiencing between focusing on the individual stories of a resident's life in a care home and refocusing on their whole story as presented in the interview sequence resonated with Ricoeur's description of interpretation arising through a dialectic movement between the whole and the parts of a text. Equally there was a dialectic movement between the stories of an individual and the stories of the group of participants. This is a sequential process that moves the emphasis from explanation and understanding, and back to explanation, as the interpretation develops.

Throughout this process the interpretation is consistently developing, with each stage of the interpretation providing the framework and the building

blocks for the subsequent interpretation. According to Ricoeur the initial interpretation begins with developing a naïve understanding of the data that aims at acquiring a sense of the whole. This generates ideas for the next phase, the structural analysis. In this phase the researcher examines the text in terms of distinct entities to explain it. The last phase consists of an interpretation of the text as a whole leading to a comprehensive understanding. This is a more sophisticated mode of understanding, developing from and supported by the first and the second phases.

This broad interpretative framework allows for movement from description to understanding but provides little direction for interaction with the data. For this reason narrative analytic methods were adopted as a systematic way of interacting with the stories that the residents told. By undertaking multiple purposeful readings at different phases of the inquiry, different interpretations were reached that resonated with the experiences of both the individual and the group of people who participated in the study. Whilst the overarching interpretative process has been outlined, a detailed account of this process has not been entered into. This may result in a gulf being created between the derivation of interpretation and the interpretation that is presented to the reader. For this reason, a rich description of the processes that led to the interpretation of the data is given in chapter 4 to enable the reader to see how the researcher reached their interpretation of the data.

Telling of the journey to others (Structure of the thesis)

One of the most pleasurable or painful aspects of any journey is recalling the events and capturing the lows and the highs when telling others about it. The account of the journey involves more than a retelling of the events that happened in a chronological order. From the initial description the traveller reflects on the happenings that they have experienced and through the process of telling imparts the meaning that they attach to their experience. The process of telling in itself gives new meaning to their journey as they

evaluate their experience and acquire new understandings of the impact that it has had on their life.

In the chapters that follow the unfolding interpretation within this inquiry is presented. In chapter 4 the theme of 'organizing, describing and interpreting the data' (introduced in Arriving at a destination, p. 81) is examined in further detail. By discussing the details of data analysis at this point in the thesis I intend to build on the earlier discussion and take the reader through the process that I had committed myself to.

The findings arising from the different levels of interpretation broadly map onto the following chapters, with the naive interpretation being presented in chapter 5, the structural interpretation being explicated in chapters 6, and the critical in-depth interpretation being presented in chapter 7. Though the multiple levels of interpretation are being presented to the reader in separate chapters, it is important to note that the interpretations are interrelated and build on each other.

In chapter 5, a picture of care home life is portrayed through the reconstructions of the stories of the 8 participants. These accounts are situated within the broader context of the participant's life and of their current living arrangements. Chapter 6 presents the shared stories that emerged through the cross-case reconstruction analysis, and in chapter 7 each of the narrative themes is examined. Chapter 8 focuses on the possibility for alternative biographies to co-exist in the care home setting. From this analysis a theoretical model is constructed to portray the elements that shape and reshape the life that residents experience in a care home. Through the sharing of the daily experiences of the people who took part in this study, and analysis of the stories that they told, insight was gained to enable movement from the taken-for-granted view of life in care homes, to a view from a different vantage point.

Chapter 4

Describing, organizing and interpreting the data

Introduction

In the previous chapter it was concluded that the process of interpretation could never lead to the truth - it led to an interpretation, an interpretation that could be complete in itself. The discussion pointed to the idea that more than one interpretation could co-exist in an inquiry. This idea rests on Gadamer's supposition that understanding between two differently situated beings occurs through a fusion of their horizons. This is a fusion that is created through dialogue, hence the idea that only one unique horizon exists is excluded, and opens up the possibility that more than one interpretation can exist of the same phenomena. Ricoeur builds on this idea and proposes that the plurality that is so inherent in the methods and theory of interpretation results from the very nature of the verbal and written text that is exchanged through dialogue. The intractable problem of plural interpretations, according to Ricoeur as translated in Thomson (1981a), is summed up in the following words:

> "There is a problem of interpretation not so much so because of the incommunicability of the psychic experience of the author, but because of the very nature of the verbal intention of the text. This intention is something other than the sum of the individual meanings of the individual sentences. A text is more than a linear succession of sentences. It is a cumulative, holistic process....the kind of plurivocity which belongs to texts as texts is something other than the polysemy of individual words in ordinary language and the ambiguity of individual sentences. This plurivocity is typical of the text considered as a whole, open to several readings and to several constructions" (p. 212).

For these reasons this chapter is devoted to an explication of the process of interpretation that was adopted in this research. Here, the reader will view the argumentation and debate that led to the formation of the interpretation. In this way the confirmability criteria proposed by Guba and Lincoln (1985) to

establish the trustworthiness of the study will be fulfilled. This is particularly important at this stage of the reporting on this study, to demonstrate that the interpretation that is presented in the subsequent chapters is more probable than other possible interpretations.

The chapter begins with a discussion of discourse as data, and then proceeds to describe the way that the data was transferred from verbal to written discourse. Following this the process of analysis, from description to interpretation, is described.

Discourse as data

The participants were asked to tell stories of their life and of their daily experiences in the care home. At the end of the interview sequence they were invited to discuss the narratives that had been identified through the preliminary analysis. So it can be concluded that language was the primary form of data in this study, which was augmented by observation of the happenings in the care home.

Though the primary aim of language is to say something about something, a direct correlation between words and the meaning that the speaker attempts to convey does not exist. Words themselves may hold multiple meanings, so speakers use words in a particular context to impart a selected meaning. Moreover, at the level of a sentence meaning can be construed in different ways. Ricoeur (1976, 1991) argues that the meaning of a sentence can be considered from an objective dimension (referring to what the sentence means), and a subjective dimension (what the speaker means). These features of language point to the importance of determining the level of articulation that is required to capture the contextual features of the spoken discourse, as well as the words that are expressed to address the research questions.

As the focus of the inquiry was on a description of everyday interactions, events and the emotions generated in those circumstances, it became evident that the level of articulation that was to become the object of inquiry was beyond that of the sentence. The participants were invited to tell stories about their life and these were captured as sequences of sentences, and at this level the unit of analysis is the discourse rather than the words or individual sentences. According to Ricoeur, as a work of discourse the text preserves the properties of a sentence, but presents them in a new constellation and this requires its own interpretation.

The discourse that was elicited in this study included accounts of specific events and those that extended beyond a single event. These are qualitatively different, representing different points along the same continuum. Though the terms 'story' and 'narrative' are sometimes used interchangeably in the literature (Greenhalgh and Hurwitz, 1999), it is recognized that they are different forms of discourse (Mischler, 1995; Plummer, 1997). Stories are informal accounts of a specific event whereas according to Priest (2000) narratives are *'greater than, more formal than, and more structured than a story'* (p. 246). Unlike a structured research interview these forms of discourse are not regulated. Stories and narratives can be retold in a way that does not reflect the chronology of time, and contradictions and inaccuracies may occur in the telling in an attempt to convey a particular meaning. These are issues that will be returned to during the discussion of the interpretative process. However, they are points that need to be highlighted when considering the nature of the data.

Verbal and written discourse

Another feature of discourse of relevance to this study is the form that was captured that could be subjected to the process of interpretation. Speaking and writing are alternative and equally fundamental modes of discourse. In this study, spoken discourse was changed from the spoken to the written form, following each interview through transcription (a process discussed in

the following section). Though this provided a permanent record of the interview, the process itself distanced the text from the conditions of its spoken form. Ricoeur refers to this process as '*distanciation*,' whereby there is a separation of the meaning that is inherent in the event of saying to the meaning being inscribed in writing, and distance is created between what is said and the intentions of the speaker.

In acknowledgement of the potential influence of the movement from the verbal to the written form on the meaning of the discourse, dialogue between the researcher and the researched was an important feature of the research design as a way of checking out and developing interpretations as the inquiry progressed. By embracing dialogue in the methodological framework for the study (see p.61) there was a movement, backward and forward, between the verbal and written form of the discourse. This enabled the discourse to be available to the researcher through verbal interaction during the interview processes and, to a wider public, through the translation to the written form.

Transferring the data from speech to text

Each of the interviews was audio-tape recorded to ensure that the participant's words, sounds and pauses were captured. The recording provided a permanent record of the interview that was available to listen to at a later date; however this was a de-contextualised record of the interview. This record lacked the visual aspects of the situation that contributed to the understanding that occurred between the researcher and the participant. Facial expressions and gestures, such as a hand movement following a short statement such as '*I told them that I had had enough*' add meaning that is not conveyed in an audio-recording. Here, different hand gestures – a shaking of the fist or holding the hand flat and in a vertical position – imply that the speaker is irritated or has reached the limits of their tolerance in a given situation, in contrast to the latter gesture that signifies that the situation ought to cease. Though video recording of the interviews was considered as a way of capturing the visual aspects of the interviews this was rejected as it was

both impractical and unacceptable to the older people who agreed to take part in the study.

As a way of enhancing the data collected from each interview, short research diary notes were made (see appendix 4 & 5). These were based on my subjective impressions of the situation as well as other details that I had remembered from the interview.

Shortly after each interview the audio recording was translated from speech to written text through a process of transcription. In those situations where the recording was inaudible notes were made from memory and checked with the participant during the following interview.

Inherent in these different modes of discourse are rules and conventions that give shape and meaning to what is being conveyed. A notable difference between verbal and written speech is the position of commas and full stops as indicators of pauses or the end of a sentence. When listening to discourse it is not always obvious where a sentence begins or where it ends, which leads to a situation where the transcriber makes judgments about the pauses that naturally occur in conversations - judgments that have the potential to shape the meaning of the written discourse. The problematic nuances so inherent in verbal discourse, such as incomplete sentences or apparently incoherent sentences also require judgments on the part of the transcriber. In recognition of these features of the transcribing process Kvale (1996) argues that there is no correct transcription because there is no correct transformation from verbal to written discourse. This is not suggesting that transcription does not have a place within qualitative research, it is pointing out the need to recognize the differences that do exist as Kvale states in the following quotation:

> "Transcripts are not copies or representations of some original reality, they are interpretative constructions that are useful tools for given purposes" (p.165).

Here, Kvale argues that the purpose rather than the form of the transcription ought to be given overriding significance and the researcher's task is to

ensure that the transcription is coherent with the purposes and aims of the research. In this study the interviews were translated from a verbal to a written form through transcription to create an aide-memoir for me to recall the stories that the older people told of their life in the care home, to provide a version of the interview accessible to public inspection and to make the content available for closer analysis. To address issues of reliability and validity the following guidelines were adopted throughout the process of transcribing:

- sticking faithfully to the words used by the participants (e.g. in Anne's first interview she used the word '*bairn*', a local term used to refer to a child; speech that was seemingly incoherent was transcribed verbatim i.e. '*and say hello Anne how are you la blab*')
- transcribing each interview in its entirety (see appendix 6 & 7 as illustrative examples)
- using capital letters to refer to individuals mentioned in the text as a way of assuring their anonymity
- describing non-verbal expression in the text (i.e. such as laughter)
- noting the existence of and duration of pauses
- where the discourse was inaudible I used brackets to convey the existence of a gap.

Managing the data

All the field notes and the transcripts were stored in computer files that were security protected. The interview transcripts were coded with a letter for each participant and given a numerical identifier to indicate the transcript's position in the interview sequence (i.e. participant 1 was given the name Anne and the first interview was coded as A1). The assignment of codes anonymised the data in a way that provided ease of access to individual files and to the whole data set that included an individual participant's sequence of interviews. Each data set was generated within a particular context so the data was also

organized to ensure that the data originating from a care home could be retrieved.

Interpreting the data

The interpretative framework

The interpretative framework developed for the study aimed to accommodate qualitatively different types of data, whilst allowing for a shift from description to interpretation, and creating a means to capture multiple interpretations of the experience of living in a care home from individuals and groups of people. The interpretative framework was inspired by the writings of Ricoeur (1976, 1991) and draws on the work of Mischler (1995) in the field of narrative analysis.

According to Ricoeur interpretation arises through a dialectic movement between the whole and the parts of a text, which facilitates a shift from the sense of the text to its reference (from what the text says to what it talks about). This is a sequential process that moves the emphasis between explanation and understanding, and back to explanation as the interpretation develops. The initial interpretation began with developing a naïve or surface understanding of the data that aimed to acquire a sense of the whole. This was followed by a structural analysis where the text was examined to explain what it says and how it was said. The third phase sought to develop a deeper understanding of what the text talked about by means of a critical in-depth interpretation. This was a more sophisticated mode of understanding, developing from and supported by the first and the second phases.

By adopting this broad framework for the analysis the emphasis shifted from the re-telling of specific stories to making generalizations from which theories could be developed. This framework, however, provided little direction for the analysis of the stories that were generated through the participant interviews. In each interview the participants told several stories and on this basis it could

be argued that the transcript approximated the form of a narrative text. In keeping with the conception of the data as a narrative text, the interpretative process drew on the methods of narrative analysis to support a unity of form. As an approach, narrative analysis seeks to see how research participants impose their order on experience and their environment, by commenting upon the relationships between events and actions in the stories that they tell. Though there are many approaches to this type of analysis (e.g. Denzin, 1989; Mischler, 1995; Plummer, 1997; Flick, 1998; Crossby, 2000) the movement from description to understanding and explanation is common to all, which is consistent with the overarching interpretative framework.

Mischler (1995) provides a useful typology of different modes of narrative analysis, suggesting that stories and narratives can be analyzed according to any one or all of the following: reference and temporal order that examines time sequence and the order of presentation or actual sequence of events in the discourse; textual coherence and structure, which explores the organization of different types and genres of stories; and function, which examines the cultural, social and psychological contexts and functions of stories and narratives. Within each of these *'types'* there are corresponding analytic approaches that serve to illuminate and make sense of the stories that people tell of their lives. For example, within the type of reference and temporal order there are analytic methods that focus on exploring the text to differentiate the 'telling' from the 'told,' approaches that reconstruct the 'told' from the 'telling,' and those that make a 'telling' from the 'told.'

At this point in the discussion each stage of the interpretative process is outlined to demonstrate consistency between the framework and the approach that was taken in the analysis. For purposes of description the interpretative framework is described as a three-stage process. In reality the boundaries between these stages were blurred as there was a continuous movement back and forth across the data.

The interpretative process

The interpretative process combined interaction with the data to explore what was said, and interpreting the data to develop an understanding of what the discourse meant. In line with the overarching framework, understanding developed from a naïve to a critical in-depth interpretation. As a way of shaping interaction with the discourse throughout this process, multiple purposeful readings were undertaken from different reader positions to illuminate different aspects of the discourse. To do this the readings were framed around questions that Plummer (1997) argued could be asked of stories:

- reading 1: what stories did the participants tell?
- reading 2: what topics and issues were discussed in the stories?
- reading 3: what topics and issues were discussed by all of the participants?
- reading 4: what were the links between these stories and the wider social world?

Though this suggests that there were only four readings during the analytic process, in reality interaction with the data was not restricted to these. The readings were purposeful activities that took place to facilitate a turn in the analysis in order to let those things that had not been previously seen be observed. Hence, the questions provided a framework for different approaches to the discourse and these mapped onto the three stages of the interpretative process.

Analysis commenced with developing a ***naive interpretation*** of the data. Though a brief description of this process is given here, a detailed account is presented later (p. 95-100). This involved interaction with the discourse following each interview to identify the stories that were told and the order of the telling of those stories (i.e. through reading one, p.97). As the interview sequence progressed, the process of reading included re-reading earlier interviews to identify emergent stories as well identifying if the stories were a retelling of those that had already been told. This text was reassembled as a

case reconstruction for each of the participants as a way of moving to an understanding of living in a care home from the perspective of each participant (each of the case reconstructions are reproduced in chapter 5).

The topics that the participants spoke of and their issues and concerns were identified through reading two. The stories that were told were unique to each participant. However, as the analysis proceeded across all of the participants' interviews similar topics appeared. This observation moved the analysis onto the ***structural interpretation*** of the discourse to examine it in order to explain what it said and how it was said (discussed p.100-102). This process led to the third reading (p.92), which facilitated coding of the text across all of the data sets. Mischler (1995) suggested that this process could lead to the identification of the collective or shared stories that permeate communities. Mischler illustrated this approach through reference to Shay's (1994) analysis of the long-term psychological effects of combat trauma of U.S. Vietnam war veterans, whereby analysis of a shared context, and comparing reactions of different people to similar events and examination of the topics that the interviewees spoke of, led to identification of the notion of combat trauma. As a group these people engaged with a collective or shared story that shaped their reactions to their circumstances. By examining this shared story understanding of trauma developed beyond a restricted medical model of post traumatic stress disorder to an understanding of the construct of combat trauma within the wider psychosocial context.

As a way of signifying that the narratives that were identified through the structural analysis were derived from the informants' separate accounts of their life in a care home, they were entitled *'Narrative themes.'* This stage of analysis concluded with examining the impact of the narrative themes on the lives of those taking part in the study. Though these narratives may have been brought into existence through the analytic process, they may have had little meaning to the participants. This brought the inquiry to the final reading (p. 107) and moved the analysis onto the ***critical in-depth interpretation*** of the data (discussed p.106-111). This stage focused on reflection-on the retelling of the participants' stories and the narrative themes to identify

connections between them. This process led to a re-examination of discourse and the various parts of the analysis that had been undertaken in the inquiry to draw the separate elements together in a way that allowed for layering of social meanings within this complex social situation. Through the synthesis of the participant's individual narratives and narrative themes, and understandings that existed in the social world about living in a care home, this phase of the interpretative process opened up the possibility for the generation of new and alternative narratives of care home life to that which already existed.

The following discussion gives further detail of each stage of the interpretative process, which has been outlined above, to enable the reader to see how I reached my interpretation of the data.

Naive interpretation

Analysis is a process that begins from the first point of contact with the subject which is of particular interest to a research study. Hence it is not restricted to the phase of the research following collection of data. In line with this premise, the process of gaining a superficial interpretation of life in care homes began as I developed the research questions, methodology and study design. When I met with the participants I developed a superficial understanding of care home life from the perspective of the resident, and this developed as I actively listened to their stories during the interview and in the subsequent process of transcription. During these activities I noted patterns in the subjects that they spoke of. These were initial impressions and observations that were captured as reflective notes following each interview. These notes were recorded in an interpretation file that was created for each participant (see appendix 4 & 5 for excerpts from Anne's interpretation file). These files also contained the outcomes from the more detailed interaction with the data, as illustrated in table 4.1.

As such, these notes captured spontaneous impressions immediately following an interview and ideas as they emerged during the research process. As the interview process proceeded the ideas that had been recorded in this way were either developed or rejected, hence an audit trail was formed of the ongoing interpretation and the dialogue that developed between the interviewee, researcher and text.

Excerpt from Anne's interpretation file: interview 1

She has had a varied lifestyle and in her earlier years she enjoyed contact with others and interacting in a range of activities. Her descriptions of her life were vivid and heavily laden with specific time markers and specific events. The most significant events appeared to occur in relation to her family. She is interested in other people, however her physical problems have had a great impact on her social relationships.

This lady had suffered enormously from different types of physical problems including arthritis, disc problems for which she had had surgery on 2 occasions, and latterly she had become partially sighted (she could only see the outline of shapes). These problems resulted in limitations on her social contact with others and the types of activities she was able to take part in.

She now has little social contact with others outside of her nursing home. Her family had either died or now her close family lived in Australasia. Contact was maintained through weekly telephone discussion.

She spoke of the nursing home staff as friends and she was interested in them as people. She desired further contact with staff, not to address physical needs but to share personal events, discuss daily activities and so on. Her desire was balanced with the knowledge that she knew that the staff were busy and had many demands placed on them by other residents, therefore she did not push to gain further contact for what appeared to be seen as "passing the time" activities.

Issues:

- Deterioration in physical health.
- The influence of personality on a resident's views about their living arrangements.
- Her need for social contact with the staff.
- The major impediments she encountered in developing and maintaining relationships with other residents.
- The impact of physical limitations on resident's relationships with each other.
- Influence of staff change on resident's experience of care in the home.

Table 4.1: Excerpt from Anne's interpretation file: interview 1

Following each interview the transcript was read to address the following question:

Reading 1: *what stories did the participants tell?*

During this reading each of the stories that the participants told were given a title or a label. This process is illustrated in appendix 6, where Anne's first interview commenced with a story that was given the title '*Anxiety provoking spinal treatment*'. This label condensed the large amount of text into briefer, succinct text whilst retaining the sense of what had been said. This process was replicated throughout each interview leading to the development of '*story files*' (see Bernard, 1988), which provided a link back to the data as well as a way of capturing the stories and descriptions in an abridged version of the interview. From Anne's first interview 24 story files were developed, and these were recorded in the participant's interpretation file (see appendix 4).

During the interviews the participants spoke of their family, career, interests and events that had happened. The stories that they told varied, some giving more emphasis to their family and others focusing on their career. A significant feature of the first interview was the way that all of the participants gave a vivid description of the circumstances that led to their entry to the care home. The later interviews focused on life in the care home and their experiences of living in that setting.

The stories differed considerably. Some were lengthy, some brief, some provided graphic details of events whereas others merely gave a sketchy outline. Some were coherent and others were disjointed, and some lacked a chronological order in the telling. These factors added to the complexity of determining the appropriate way of retelling the stories. Faced with these problems I returned to the research questions and aims of the study. This directed my attention to developing an abridged version of the participants' lives and their experiences from the storylines that had been mapped in their story files in the form of a case reconstruction. This process is akin to what Mischler (1995) referred to as discerning the underlying plot in a text as described here:

> 'story designates the narrated events, abstracted from their disposition in the text and reconstructed in their chronological order, together with the participants in these events. This is what in other terms we may think of as the underlying plot, which must be analytically abstracted from the text. The text is what we read. In it events do not necessarily appear in chronological order, the characteristics of participants are dispersed throughout, and all the items of the narrative content are filtered through some prism or perspective. The text is the only aspect available to the reader.....the successive events that constitute the story-line of a narrative are only retrospectively comprehensible, after the plot structure of which they are functions has become perceivable' (p.104).

The case reconstruction for each of the participants was framed around four categories of narrated events as these permeated all of the interviews. These were:

- interviewee profile – biographical details of the participants' lives
- life as a resident in a care home
- relating to others in the care home (relating to fellow residents and to the staff)
- the biographical significance of care.

What was included in this retold story of their life had been discussed with the participant during the final interview with them. In this sense the case reconstructions were co-authored by the participant and the researcher. The case reconstruction resulted in an analytic representation of the participants' lives prior to and following the move to a care home. This was a reconstruction of a *'told from the telling'* (in line with Mischler,1992) that became the narrative that was subsequently interpreted. In chapter 5, the eight case reconstructions emerging from this process are presented as the interpretation arising from this phase of the inquiry.

Reading 2: *what topics and issues were discussed in the stories?*

This stage of the analysis provided the opportunity to revisit the interviews from a different reader position. Whilst the focus of the first reading was on the identification of stories that were told, this reading sought to extract the topics and issues that were discussed within and across stories. For example,

the following story was entitled '*Deteriorating health and making decisions about long-term care.'*

> *"Then I took another attack of crippling arthritis which they diagnosed later as arthritis in the spine. The surgeon I saw said there was no way could another surgeon go in to the back again. They had taken part of my hip bone out to put in my spine and he said you will not find a surgeon who would do that - it is a question of learning to live with it. The pain was atrocious. I was in and out of hospital and then back home. They said I would need someone to look after me. It was a five bed roomed up and down house that I lived in. It was a lovely home. But I didn't want people walking in and out that I didn't know. I had an alarm put on and I thought they would be walking in and setting the alarm off. I didn't want that sort of home help and they suggested that I could move to a nursing home and this is where I moved to."* (Anne interview 1)

This story is complete in itself, giving details of the circumstances that led to the move to a care home. Within this story many topics are introduced, such as living with chronic ill-health, the need for long term care and loss of independence, and involvement in the decision-making process about type of long-term care. The topic of 'loss' – loss of health, functional ability, home and independence – is an inherent part of this story, but when other stories are re-read the multiple losses that this woman experienced (loss of a beloved sister, loss of close, frequent contact with her only son and loss of a satisfying career) were revealed.

The topics and issues that were identified during this reading of the interviews were given a code. The codes were recorded in a '*topic file'* in the participant's interpretation file. As the coding progressed the initial topics and issues that had been identified were reviewed, revised and extended. The code 'loss', for example, was extended to denote the 'multiple losses' that this woman had experienced (see appendix 4).

Through this second reading of the interviews a different sense of what the text said was created and this provided an alternative picture of care home life from that which had been produced through the identification of the stories. By this stage different descriptions or alternative surface interpretations of the data had been produced, but no more. The interpretation moved from this level of description by revisiting this same question to explore what the

participants were saying about the topics and issues that had been extracted from the data, so this reading extended into the next phase of interpretation.

Structural interpretation

The development of the topic-files was a researcher-led activity, which had the potential to shape understanding in ways that did not resonate with the participants' experiences. There needed to be a coming together to develop a shared understanding of what the participants were saying rather than continuing to develop an interpretation of what the researcher thought that these people had said. Hence, an important feature of the inquiry was dialogue between the participants and the researcher.

Developing a dialogue

Developing a shared understanding of life in a care home from the standpoint of the resident needed to be a circular rather than a linear process. This was achieved by revisiting the story files and topic files that had been created following transcription during later interviews and in particular during the final interview. This enabled the participants and researcher to discuss the topic codes and to review, revise and extend them if differences in understanding existed.

The circularity of the process of checking and developing understanding is illustrated through the evolution of the code '*resisting increased dependence*' from Edna's interviews. During the initial interviews she told stories about the different ways that she strived to maintain her independence in the care home. She developed tools that enabled her to open and close the patio room doors without assistance, her audiovisual equipment was positioned so she could control it, she self-medicated and she developed an exercise program to maintain and enhance her ability to move herself in her wheelchair. This is illustrated in the following extract:

> *"I have never gone in* (the dining room) *at breakfast time. When I came in they said that I could have my breakfast in my room. I have always*

had it in here and I like it better. I take my own pills. I keep them all myself. The others get them dolled out and I don't like that."

(Edna: interview 2)

Following this interview the initial code was identified and labelled '*Developing/negotiating ways to self-care*'. When this topic was raised in later interviews she told stories of the ways that she strived to do things by herself. In the following extract she described her efforts to use her remaining leg to move her wheelchair. This took great effort but she did this to maintain her existing level of functioning, thereby retaining a facet of independence in the care home. She also discusses the circumstances that did not support her in her endeavours:

Edna: *"I used to use my foot well but since I fell out of bed I don't use it quite as much you know. I don't particularly want to have an electric one [wheelchair] but I might have to get one..."*
Researcher: *"You have mentioned that before. Why have you resisted moving to an electric wheelchair?"*
Edna: *"I usually use that foot [her only leg] to do this [demonstrating that she can move herself in her chair] and you don't in an electric chair."*
Researcher: *"Do you like the exercise?"*
Edna: *"Well I do because I use it a lot and I will probably get it back again. I don't want, but I think that I will have to. Matron would like me to have one and I just keep on saying no. Well I would just sit and I don't do anything you know."*
Researcher: *"Yes."*
Edna: *"And they [the staff] don't worry about that. Quite a lot of them [other residents] come up for tea or a meal and they get pushed in a chair."*

(Edna: interview 4)

"Well when I go down to the loo I let them [staff] take me and then I try to bring myself back. You see you start off coming down and then somebody says well I will give you a push. I say no I don't want to be pushed but sometimes I let them."

(Edna: interview 5)

During the final interview Edna was asked directly about independence and the way that her circumstances impinged on her experience of this. It was important to revisit this subject because her struggle to maintain her independence had been a dominant narrative that wove its way throughout the interviews. This discussion was an attempt to distinguish the construct of the code and affirm the connectedness of independence, self-care, her actions to maintain her current level of independence and the staff

actions/circumstances that fostered dependency. From this analysis the code '*maintaining self-care whilst resisting increased dependence'* was developed:

> Researcher: *"Is maintaining your independence crucial to you? Some of the examples that you discussed were the way that you developed little tools to open and close your [patio] doors rather than relying on the staff to do that."*
> Edna: *"Oh down there and there. Oh yes I have it all done."*
> Researcher: *"And the way that you resisted moving to an electric wheelchair."*
> Edna: *"I haven't yet."*
> Researcher: *"Is that about maintaining your independence?"*
> Edna: *"Yes, I think that matron would rather have me in an electric chair but I don't want one."*
> Researcher: *"Ah ah."*
> Edna: *"I think that they all have them. Well not all of them but you know. I prefer my own. I get to use my leg and I get to keep going so I can do things myself."*
>
> (Edna: interview 8)

Through this process of moving back and forth between the individual parts of an interview sequence and the whole, a dialogue was built up between the researcher and informant in an attempt to gain a shared understanding of what they were saying about their life in the care home. As there were eight participants in this inquiry, this process resulted in multiple interpretations of the same experience. The generation of the story files and the topic files provided a way of representing the unique experiences of these people, but it also highlighted similarities in the topics and issues that they had spoken of. With this observation the inquiry moved onto the third reading that extended the inquiry beyond the experience of individuals.

Reading 3: *what topics and issues were discussed by all of the participants?* As the inquiry progressed and the topic files developed, it was apparent that some of the topics were discussed throughout an individual's interview sequence and by all of the participants. Comparing and contrasting all of the participants' topic-files highlighted similarities and differences. There were, however, difficulties in doing this. The coding that was recorded in the topic files was undertaken for each of the participants without reference to the coding of other participant's interviews. The code '*maintaining self-care whilst resisting increased dependence',* for instance, portrayed Edna's experience

but not the experience of others. The constructs of this code - self-care, independence, dependency, coping strategies - resonated closely to aspects of the codes listed in the topic files of the other participants. This observation made it clear that the question posed for reading 3 would be partially addressed by comparing the topics files that had already been created. A third reading was required, therefore, to develop a more comprehensive understanding of what these people had said.

During the third re-reading of the total data set the uniqueness of the participant's lives was evident (as depicted in chapter 5). There were topics that they all spoke of, affirming the impression gained from the earlier comparison of the topic files. In an attempt to develop an analytic framework to undertake a cross-case-reconstruction analysis of the participant's lives, the text was examined to identify common subjects that they all spoke about. The first of these topics concerned the circumstances and the decision processes that resulted in the move to a care home (i.e. *moving-in).* For the majority of the participants this was a move that resulted from need and not preference, and it was a permanent change in their living arrangements. Although they all held preconceptions of what it was like to live in a care home, they needed to make adjustments to their new living conditions. Some of these changes concerned adjusting to living with disease and limited functional ability as a result of the illness that had brought them to the situation where they required long-term sustained care and support. *Settling-in,* by making adjustments to life in the care home, therefore, was a second unifying subject across the data set.

A major feature of all of the interviews was the numerous stories of the daily happenings in the care home. This is not surprising as this was the central focus of the inquiry. These discussions were embodied in the third subject, *Living-in* a care home. The final subject that cut across the interviews concerned people, residents and staff, leaving the care home, so this was entitled '*Moving-on.*'

The four themes - *moving-in, settling-in, living-in* and *moving-on* - were the transitions that these people had encountered throughout their life as a resident. These subjects broadly map onto the professional and academic literature that examines transitions in later life in relation to long-term care. (see for example Tobin and Lieberman, 1987; Guthiel, 1991; Patterson, 1995; Nay, 1995, Reed and Payton, 1996). For this reason the points of transition that the participants discussed were used as a framework for the analysis across the cases in this study. These subjects were used throughout the third reading phase of the inquiry as an analytic framework to explore whether there were topics or issues that all of the participants spoke of. By examining the text in this way the topics and issues that threaded their way through the interviews were identifiable. These topics and issues were grounded in the stories that the participants told. As more stories were told of the same topics and issues, codes were developed to denote the sense of what became the story of many voices. As this stage of the inquiry progressed, the codes were categorized into themes and at the point that they could no longer be assimilated into embracing themes the analysis concluded. Six narrative themes were identified through this process, which are presented in chapter 6. The narrative themes were:

- Narrative theme 1: Caring for oneself / being cared for
- Narrative theme 2: Being in control / losing control
- Narrative theme 3: Relating to others / putting up with others
- Narrative theme 4: Active users and choosers of space / occupying space
- Narrative theme 5: Engaging in meaningful activity / lacking meaningful activity
- Narrative theme 6: Having an enriched private life / an impoverished private life.

These narrative themes embodied the parallelisms of the lives of residents. All of the participants experienced the narratives of care, control, living with others in the home and so on. Yet the way that they interacted with each of these narratives contributed to their unique experience of life as a resident. In

this sense it could be argued that the participants were not passive recipients of care, they were active agents attempting to shape the lives that they lived in the care home through their construction of each of the six narrative themes that were identified through the analytic process.

This understanding of the way that older people live in care homes pointed to two further directions for the inquiry. First, it pointed to the possibility that residents adopted strategies in an attempt to influence their life in the care home, and secondly, if this was the case, that residents were active agents seeking to shape their own lives within this social setting. Identification of these possibilities highlighted the need for a further analysis of the data. Returning to the narrative interviews, a further thematic analysis was undertaken that specifically focused on the following questions to examine these possibilities:

- Do residents employ strategies to shape their life in a care home? And if this is the case,
- What strategies do residents adopt in their daily lives?

The results of this analysis are presented in the latter part of chapter 6. These findings provided evidence that residents use many different strategies to tailor their life in ways that promote their independence and enable them to do the things that they find meaningful. In the discussion of Edna's striving to maintain movement in her remaining leg, in the previous section, she attempted to find ways to 'self-care' and retain 'control' by making the decision to keep her manual wheelchair. She acknowledged that her fellow residents, the majority of wheelchair users, acquiesced to the manager's decision for residents to use electric wheelchairs. She, however, maintained her position that she wanted to use a manual chair prior to and during the interviews. This example, and others, pointed to the possibility that something other than the existence of the narrative themes existed within the care home setting and suggested that residents construct these narratives in different ways. This observation paved the way to re-examine the text in a more critical way by moving beyond the discourse so far examined, and to explore the lives of

these individuals in the wider social context embodied in the professional and academic literature concerning living in a care home.

Critical in-depth interpretation

This stage of the inquiry commenced with a reflection on the individual stories that had been retold as case reconstructions and the narrative themes. This process highlighted that the narrative themes were qualitatively different to the individual stories that had been elicited through the narrative interviews. The individual stories described and referred to the participants' actual experiences, whereas the narrative themes referred to concepts that existed within those experiences. In the stories about involvement or lack of involvement in decision-making processes, for instance, the participants spoke of what they did and what happened to them. In this case they did not make reference to the abstract idea of 'control', but to the way that they experienced the various dimensions of this concept, such as 'being in control' or 'losing control', in their everyday life. In this sense the narrative themes were an implicit feature of the participants' daily life, but at the same time they were distanced from their immediate experience. The distance that had been created between the participant and their experiences was addressed by refocusing the analysis to examine the way that the narrative themes played out in the lives of those taking part in the inquiry.

By seeking connections between the individual narratives and narrative themes, patterns were identified. Some of the participants had developed innovative ways of maintaining their independence in the care home and were able to self-care in some aspects of their lives. Others were highly reliant on the staff for care and support in every aspect of their lives. Some made decisions and were able to act on their choices, whereas others made decisions and were unable to exercise their choices and were unsupported to do so. These are illustrative examples of the 6 narrative themes that serve the purpose of highlighting the way that reflection-on the individual narratives and

narrative themes developed understanding, whilst affirming consistency between the individual narrative and narrative themes.

Whilst the initial phase of this stage of the inquiry highlighted the consistency between the individual narratives and narrative themes, there was no evidence that the findings resonated with what was already known about the experiences of other people prior to this inquiry. This led to consideration of the global meaning of the text through a fourth reading.

Reading 4: *What were the links between these stories and the wider social world?*

The fourth reading focused on the links between the individual narratives and narrative themes and the wider social world by taking into account the researchers pre-understanding of this subject, contemporary debates in the literature, and the outcomes of the earlier stages of analysis.

As I entered this stage of the inquiry I recognized the importance of taking into account of my pre-understandings of this subject. As the inquiry progressed my understandings of care home life changed from those that I had held that provided the impetus to carry out this study (see chapter 1). Whilst undertaking this study I engaged with the world of the care home from many different positions. Meeting with and listening to the stories of the participants provided a direct interface with the discourse that is reported in this thesis. Whilst doing this my work as a researcher in an academic setting provided unique opportunities to undertake research with older people living in different settings and to hear of their issues and concerns.

In one study that was commissioned by the Joseph Rowntree Foundation to explore older peoples' involvement in policy, planning and research, I visited innovative extra-care housing developments where assistive technology was being piloted (Reed et al 2005). These developments were not available to the participants in this inquiry, yet these had the potential to alter the environment of the care home to provide residents with different opportunities to self-care and to carry out the choices that they made.

In another study (Reed et al, 2003c) that investigated older people's views of growing older, I had the opportunity to interview older people who lived in a range of settings - a care home, sheltered accommodation and private housing - to listen to them to find out what they identified as good health in later life. These preliminary discussions provided a background for a review of the literature that focused on healthy, comfortable ageing. Whilst this experience broadened my knowledge of the literature concerning ageing, it caused me to reflect on what the participants in this inquiry were telling and to interpret their stories in ways that changed my standpoint. For example, those who took part in the 'Getting old is not for cowards' project (Reed et al, 2003c) spoke of their capacity for enjoyment and fulfilment although they lived with chronic ill-health and disability. They used their material, caring and health resources to find ways to enjoy life that was not dependent on their physical abilities. Knowledge of this strategy focused my attention on the ways that the participants in this inquiry modified aspects of their daily life to enable them to do what they wanted to do.

Though these experiences had the potential to enhance my understanding of care home life by opening up my understanding to different possibilities for living in a supported group living environment, I needed to keep a constant check that this interpretation considered and questioned the knowledge gained from these various experiences, whilst grounding the inquiry in the world view of those taking part in this study. To do this I noted the ideas that were developing from my various research activities in a research journal. By capturing ideas in this way I was able to move the examination of contemporary debates that I was commencing from a platform that only considered those debates that were taking place within the literature, to include debates and innovative developments that had not yet reached the literature.

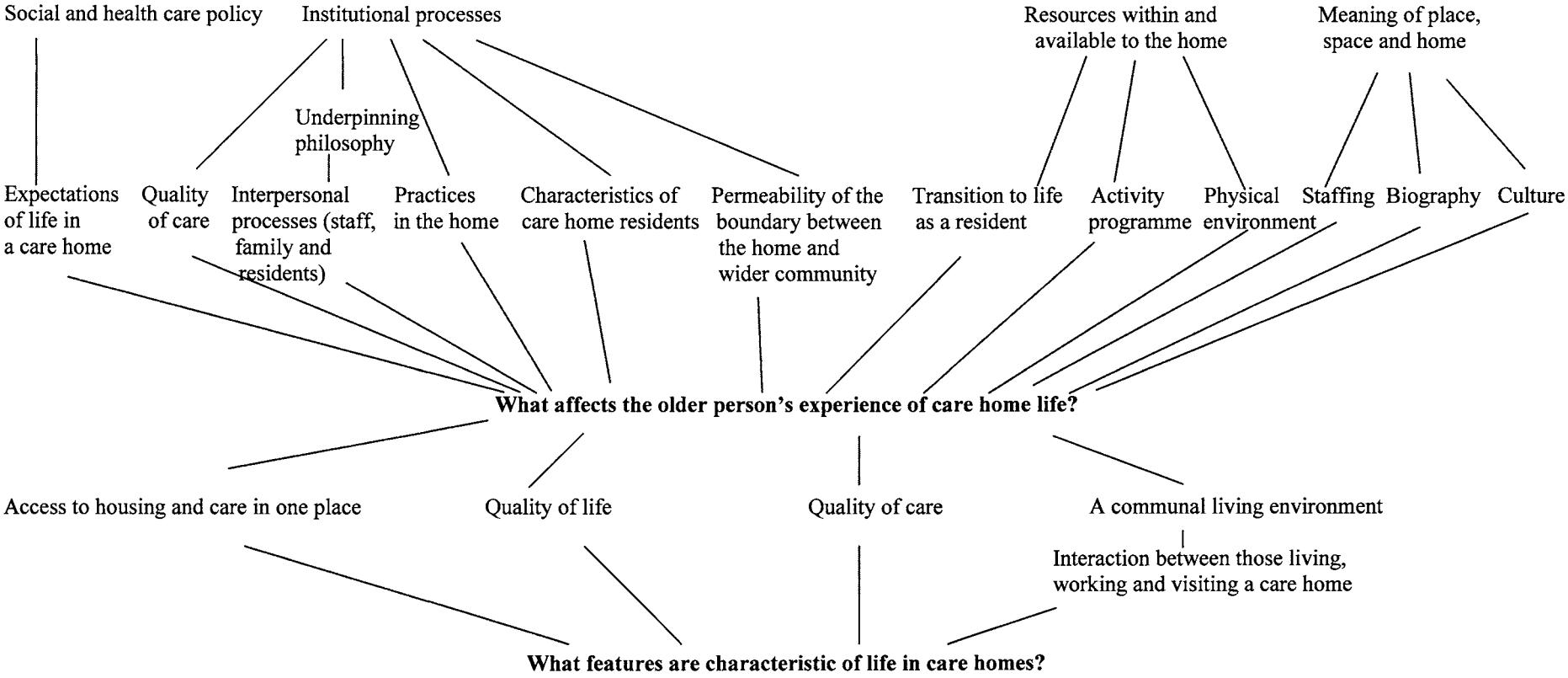
The reflection on my experiences led onto an in-depth reading of the policy, academic and practice literature relating to life and work in care homes. In order to ensure that this reading was comprehensive as well as structured, the literature was mapped using a subject relevance tree, an approach

described by Hart (1998). This process facilitates the categorisation of literature into one of many sub-themes of the major topic of interest in an investigation. By mapping the literature concerning the long-term care of older people in care homes in this way it became clear that this literature was diverse (see figure 4.1).

Moreover, the development of the subject relevance tree highlighted themes and sub themes within the literature that resonated with the narrative themes that had been identified through this inquiry. There was, for instance, different bodies of literature that addressed the various facets of the narrative theme 'Caring for oneself / being cared for'. There was material concerning the characteristics of care home residents, which highlighted the range of need within this population, such as assistance with self-care tasks (see for example, Bebbington et al, 2001; Office of Fair Trading, 2005); a category of literature about the way that the physical environment could be modified to counter the impact of disability and enhance independence (for example, Heywood, Oldman and Means, 2002; Peace and Reynolds, 2004; Swann, 2005); and literature about resources that optimise functional ability (for example, Swann, 2004). This was the case for each narrative theme.

Through examination of the literature relating to each of the narrative themes, understanding of the stories developed within a broader frame of reference. Equally, as the narrative themes developed, gaps in the literature were highlighted. This is illustrated by reference to the narrative theme 'Relating to others / putting up with others' and the body of literature that had been categorised as 'Interpersonal processes'. Within this body of literature the importance of interpersonal relationships in later life is addressed (see p. 39 for a discussion of this). A sub-category in this literature is interpersonal interaction within the care home setting, which focuses largely on relationships between staff and residents (for example, Diamond, 1992, McNormack, 1998) and between residents and their families (for example, Ryan and Scullion, 2000; Davies, 2001). In contrast there is a small and growing literature concerning relationships between residents (for example, Mattiasson and Andersson,1997; Reed and Roskell Payton, 1996) and little

Figure 4.1 : Subject relevance tree on the literature of the influences on older peoples' experience of care home life



discussion of relationships between residents and their friends, other than discussion papers within the practice literature that highlight the importance of maintaining existing relationships following the move to a care home (for example, Johnson, 2004).

This same process (of developing the narrative themes through an iterative process of reading the transcripts and reading related literature) led to greater understanding of the strategies that residents adopt to influence their circumstances, and pointed to other features of the care home climate that impacted on the resident's experience. For example, the participants told stories about what they did to change their circumstances, which was either with or without negotiation with the staff. They did not discuss the strategies that staff utilized in their daily practice, such as providing personalized care. Such gaps were carefully noted as these pointed to a social world that existed. However, this had so far been hidden behind the discourse that had to this point taken the centre ground in the inquiry.

This stage of the inquiry concluded in the translation of the on-going dialogue that had taken place throughout the inquiry into a written discourse that captured the separate parts of the inquiry as separate but layered interpretations of life in a care home from the perspective of those living in that setting.

Summary

This chapter sought to present a rich description of the interpretative process that took place in this inquiry. The step-by-step account was given to make transparent what was essentially an invisible process. Any interpretation can be challenged, however, by making visible the interpretative process that took place. Here, the reader has been provided with knowledge to inform their judgement of the interpretation contained in the following chapters whether it is viable and based on sound principles.

Chapter 5

Life in a care home
- naive interpretation

Introduction

In this chapter, the stories of eight older people are retold. Through these stories we see the social world of the care home from the perspective of residents. This is a complex social world that is collectively created by residents, staff, families and visitors within a physical building. This is a world that was designed by past creators and not by the present inhabitants, yet the present inhabitants all too readily realize that they are part of actions and events that were not all of their making. Every inhabitant of this world is a main character in their own story whilst playing subordinate parts in the stories of others.

In the same way that an author presents one story among many possibilities, the participants told stories about their life prior to and following the move to a care home. The act of telling stories is, in itself, a fairly factual process that involves people and the events that happen to them. One consequence of the participants being invited to take part in a series of interviews, however, was the way that they told many stories, and occasionally these concerned the same situations. Each telling of the story was unique, highlighting different facets of the events that took place in their lives. With these complexities in mind, the data derived from this study will be presented to the reader as reconstructions of the stories that were told by the participants as a way of remaining faithful to their accounts of their lives. Through these case reconstructions we hear of their experiences. The strategies they developed for living out their lives in the care home environment are introduced at this point in the discussion and returned to in chapter 6.

Getting to know the participants

Before the detailed accounts of the participants' experiences are presented, an overview of these diverse stories is given to provide the reader with a framework to recall the individual stories. All of the participants moved to a care home following deterioration in their physical and/or mental abilities. This was a time of great change for every one of them. They were experiencing decline in their personal abilities, as well as attempting to cope with this major life transition. In keeping with the findings of Brook (1987) and Reed and Roskell Payton (1996), amongst others, these individuals made active adjustments in their lives as they made the transition to living in a care home. One of the major adjustments that they all faced was living with dependency - they were now reliant on others to assist them in their daily lives to meet their personal needs.

What they did and how they reacted to their circumstances differed markedly. Some felt that their lives had been enriched as they entered a place where they had increased opportunities to meet and be with other people. Others felt that they were restricted - they had little choice about what they did and the people that they interacted with. The stories that they told of their lives highlighted their uniqueness and their individualized way of living that they had developed since moving to the home. Table 5.1 gives an overview of their journey into the care home and their life in that environment. The categories used in the table were derived from an analysis of the key topics that they spoke of - the circumstances that led to their entry to the care home, their perceptions of living in the care home, continuity or change in their social relationships, their relationships with others who were living and working in the home and their daily activities.

Resident	Care home Residence	The move to care	Residents' perception of life in the care home	Contact with family / friends	Relationship with other residents	Relationship with staff	Regular activities
Anne 76 years old	Care home A 6 years	Her health had deteriorated and she chose to move to care rather than have care at home. Her choice of care home was supported by information from her son and friend.	Everyday is much the same in the home. She attempted to change this by doing things that interested and satisfied her, with the support of the staff.	She has sustained her relationship with her only son and her life long friend through regular visits and telephone conversations.	She knows of her fellow residents through the discussions that she hears from the privacy of her room. Her visual impairment resulted in difficulty in sustaining interaction with other residents.	She has actively sought to develop intimate relationships with staff. However the majority of social interactions with them are functional rather than relational.	She primarily pursues her interests, such as listening to the talking books and the radio within her room. She rarely takes part in communal activities within the home.
Beatrice 86 years old	Care home A 2 years	Following a stroke, she moved to the nursing home. The decision to do this was mainly driven by the professionals' assessment of her need rather than her choice.	Since moving to the home time appears to have stood still. Her daily life is routinised and lacking in the activities that she finds meaningful.	Whilst close family members visit occasionally, visits from friends ceased when she moved from the sheltered housing complex.	She sees the same people everyday in the public lounge. She knows them and co-exists with them but she does not consider them to be her friends.	She interacts with the staff on a functional basis - they are the providers of care and she is the recipient of their services.	Her day-to-day life is mainly lived with the group of wheelchair dependent residents. Though much time is spent sitting together in the lounge they do engage in occasional communal activities.
Charles 88 years old	Care home B 6 years	Although he was offered community care, he chose to move to the care home after the amputation of his left leg.	The care home is viewed as a place where he is supported to develop a new and satisfying life within his physical restrictions.	Family and friends are scheduled into his itinerary of daily visitors.	He interacts with fellow residents. However these relationships have developed no further. He feels that he has little in common with other residents.	He enjoys interacting with staff to discuss issues of mutual interest, and has developed more intimate relationship with some staff.	He takes an active interest in the happenings in the care home whilst actively pursuing his own interests.
Doris 84 years old	Care home B 1.5 years	Following a stroke, which left her unable to care for herself, she agreed to take part in a trial placement in a care home of her own choice. Following this she decided to stay in the home.	The care home provided an unanticipated opportunity to extend her social network, thus the loneliness that she had experienced in her later years reduced.	Her nephew visits regularly. Contact with her friends, however, reduced a long time prior to the move to the home and was not re-established.	She enjoys interacting with fellow residents and has developed friendships with some of them.	She has developed quite close relationships with some staff and enjoys her routine of greeting them in the morning as they arrive in the home. She observes and comments on their working practice.	She is an active participant in the communal activities that take place in the home, and she works with staff to organize the social programme.

Table 5.1: An overview of the participants in the study

Resident	Care home Residence	The move to care	Residents' perception of life in the care home	Contact with family / friends	Relationship with other residents	Relationship with staff	Regular activities
Edna 83 years old	Care home C 4 years	After the amputation of her right leg she made the decision to move to a nursing home that she had known for a long time.	Since moving to care she has become increasingly dependent on the support of staff. To regain some independence she has adapted her environment to enable her to do the things that she enjoys.	As the health of family and friends has declined she sees less of them. Contact has been maintained in other ways like telephone calls and letters.	Though she enjoyed being with her fellow residents and interacting with them, the expressive aphasia she experienced limited her ability to chat with them.	She mainly interacts with the staff in a functional way - to assess and negotiate the care that she needs.	She engages in many activities - i.e. letter writing and group quizzes. As her communication ability deteriorated she spent more time observing the activities of others rather than participating.
Florence 95 years old	Care home C 2.5 years	The stroke left her debilitated and unable to care for herself. She knew of this care home and her care manager supported her to make the move to it.	Life in the care home was viewed as living a life of increasing dependency. Within the routines she created opportunities to exercise her independence and to be herself.	All the family and friends from her generation had died. Younger relatives live far away and send flowers and letters.	She felt that she had little in common with her fellow residents. Whilst she participated in communal activities, she did not seek any further contact with them.	Her interaction with the care home staff was focused on the services and the activities that they provided for her.	She built on the care services by paying for personal carers. These people enabled her to do the things that she valued such as being taken out for walks in her wheelchair.
Gloria 73 years old	Care home D 6 years	From mid-life she endured chronic ill-health. When her husband, her main carer, suddenly died she was left with no other choice but to move to a care home.	Her continual deterioration signifies that the care home is the place where she will die. Physical frailty has resulted in total dependence on care staff for assistance with all aspects of personal care.	Her brother visits regularly and she receives occasional visits from nephews and nieces.	She is a shy person who has never liked being in a group. However, she accepts that being with others is an inherent part of life in a care home. She views some interaction with other residents as annoying and unpleasant.	All of her interaction with staff serves functional outcomes.	Most of the time she sits and watches other people in the lounge. When she is occasionally pain-free she attempts to take part in communal activities, but her functional abilities limit her participation.
Harriet 80 years old	Care home D 3 years	When her sister was unable to continue to care for her, after she had had the stroke, she was informed that she had to move to a care home.	She views life in the care home as monotonous. She did not want to move to the care home and she does not like being there.	Her sisters and brother-in-law visit frequently. They take her on walks to the nearby park and shops. She values this greatly.	She experiences difficult relationships with fellow residents. Though she desires their companionship she is irritated by their behaviour.	She interacts with the staff mainly on a functional basis - they are the providers of care and she is the recipient of their services.	She spends most of her time with the same residents in the lounge area of the home. Though she watches the television and chats occasionally with other people she does little else.

Table 5.1 continued: An overview of the participants in the study

Telling the told story

The participants lived in four very different care homes. The literature that was discussed in chapter 2 suggests that the care environment has an effect on the experiences of residents. At its best it is a setting that enables the older person to achieve their optimum quality of life, and nurtures the individual through the provision of the care that they need. At its worst it is a setting that has been described as eroding the older person's sense of worth, and increasing their feelings of vulnerability and powerlessness (for example, Davies, 2001a). For this reason the care home where the participants live is described at the beginning of each of the following four subdivisions included in this chapter. The descriptions of the care homes are derived from the perspective of the staff that work in the homes. This is given first, to give a picture of the informant's living circumstances rather than privileging this data over the residents' accounts and perceptions of their life in the home.

The description of the care home is followed by the case reconstructions of two older people who live in the home. Each account is different in an attempt to reflect the views and priorities of the older person rather than the interpretations that were made by the researcher.

The case reconstructions commence with an interview profile that highlights the narratives that pervaded the participants' earlier lives. This was, for example, a narrative of homemaker, devoted partner and/or active member of the workforce. The changing narrative that they experienced, of disease and decline, is briefly discussed and followed by a description of their move to a care home (further biographical details are presented in appendix 8). Attention then shifts in the case reconstructions to the participant's life as a resident. This is introduced with a summary statement that reflects their narrative of life in the care home. These summary statements were derived from the interviews, as direct quotations, or they were constructed by the researcher and discussed with the participant during the final interview. Here, stories of their regular activities and relationships with others in the care home are retold. These encapsulate their views of their world as they saw it.

Each case reconstruction ends with a final part that details the biographical significance of the participant's life in the care home. This part was co-authored following the final interview as a way of representing the shared understanding that had been reached between the participant and the researcher. Presenting the data in this way highlights the vibrant or, in some cases, the stagnant lives that these people had lived in the care home. Their lives were markedly different, even in the same setting, which challenges the narrative that is all too often presented - that care homes homogenise residents' lives so that their separate biographies become the common story (see, for example, Paterniti, 2000). In summary, each of the subsequent subdivisions of this chapter include:

- A descriptor of the care home from the staff perspective
- Case reconstruction of two residents who live in the care home that include
    - Interviewee profile – Getting to know the resident
    - Life as a resident in the care home
        - Relating to others in the care home
    - The biographical significance of care.

Care home A where Anne and Beatrice live

Care home A

This nursing home was registered to provide 20 resident placements. At the time of data collection, four men and 16 women lived in the home, many of whom had lived in the local area throughout their lives, so the home was a familiar building to them prior to moving there.

The home was purpose-built on a site that was located in a quiet residential area of a larger city, near to a few shops, restaurants and a school. The building had two floors that included private and public areas. The residents' private rooms consisted of two adjacent areas - a bedroom with en-suite facilities, including a shower, wash basin and toilet. The public areas of the

home included service (kitchen, laundry etc) and communal facilities (dining room on both floors and three lounges - two with televisions and the other was a quiet room that had veranda access to a lawned garden). Of the communal lounges two were regularly used by the same residents each day, and the quiet lounge was rarely used by residents.

At the commencement of data collection the manager promoted an '*open door policy,*' which encouraged communication between residents, their families and staff. This exchange of information was supported by the team and key worker systems that were operating in the home. The aim of these approaches to the management of care was to enable staff to develop an understanding of the resident's needs and preferences, and on the basis of this information provide individualised care. As key workers, the care assistants frequently worked with the same residents, thereby building familiarity in their interaction with each other. The importance of staff knowing the resident, and the residents being familiar with staff, was brought to the attention of the regular staff in the home through the comments and reaction of residents:

> *"I went in to see Beatrice the other day and she said 'Where have you been?' I said 'I have been off for two days.' And then she said 'I have had this girl coming in and she nearly dropped me.' You don't want that! Well Mary, if she sees a strange face she cries."*
>
> (Care assistant)

Through the key worker system the care staff attempted to sustain continuity in care for the residents by monitoring what took place, even when they had been off-duty as discussed by Anne's care worker in the following extract:

> *"If I went in to see Anne and her nails weren't very nice, I could say to the other staff on the floor - 'Look I am her key worker, I was not in yesterday, so could you make sure, on the days that I am not in that her nails are kept well manicured and so on you know."*
>
> (Care assistant)

In addition to addressing the needs of individual residents, the staff attempted to build a community in the home that had all the services and resources to be

self-sufficient. Hence, great importance was attached to the hairdressing, postal and banking services; the advocacy group; residents meetings; and the programme of activities that ran throughout the week.

As data collection proceeded the home went through a turbulent time. This commenced with the change in ownership of the home and the appointment of a new manager. Then a new approach to care, based on strict budgetary control, was introduced. With this, the care staff felt that they were no longer able to provide the intimate care that they felt that they provided, nor the resources to support activities in the home:

> Carer 1: *"Yeah I mean they have not even got board games in here for the residents."*
> Carer 2: *"And like I was saying other carers have gone upstairs and there are only a few of us down here now. Really we have got no time. And you go into the lounge and they are just like sitting, falling asleep."*
> Carer 1: *"Falling asleep with boredom."*
>
> (Care assistants)

It became increasingly noticeable to residents that staff were leaving the home and this disrupted the continuity in care, which they had previously experienced (see p. 123 Anne's case reconstruction). Now the focus of the carers' attention was firmly fixed on getting through the daily workload with staff who were relatively unfamiliar with the residents.

1: Case reconstruction: Anne

Getting to know Anne

Throughout Anne's life being a member of a close interdependent family was important. Her involvement in this family had led her to fulfil many roles – the role of a mother, a sister, a carer for ageing parents - which she balanced with time devoted to her work in sales in a large department store. She described her early adult years as happy but busy times.

From her thirties onwards she experienced chronic back problems that were related to arthritis in her spine. As a consequence of this physical problem she took early retirement from work. The years following this were characterised by progressive physical and functional decline. For many years the support of a network of close long-term friends enabled her to maintain her independence and live alone, in a large five bedroom terraced house. Her only son had moved to Australasia, and the death of other family members had left her dependent on the help of these friends. She was determined to be as independent as possible for as long as possible and she declined the many offers from her son to live with him and his grown up family in Australasia.

As her abilities deteriorated further she made the decision to move to a care home rather than accept the community care package that she was offered by the statutory services. With the help of her son and friend she selected a care home and moved there. Since this time her physical condition continued to deteriorate. At the point of commencing this study she could no longer walk, but was able to move her wheel chair by herself. She was slightly deaf and used a hearing aid to assist her to hear. In addition, she was diagnosed with a chronic visual problem. Initially this affected only her peripheral vision. Now she can only distinguish contrasting colours and only see forms as shadow. She has now lived in the home for six years.

Life as a resident: seeking ways to change the sameness of it all

When asked about her day-to-day life Anne highlighted the monotony of the life that she lived - "*the sameness of it all*". Much of her life revolved around daily and weekly routines that she had developed to fill in time:

> *"I go down the corridor in the mornings to see if there is any mail or tapes left in the post. They come about 11.00am and I go about then. And that fills the morning up and I chat to whoever is passing by in the staff.....You are just looking at passing the time I suppose."* (interview 3)

Following her morning visit to collect her post she usually returned to her room to listen to the morning news and her talking books:

"I have been listening to my story books, that I get from the RNIB and the library who come every four weeks with the library bus. That is my biggest hobby because I can't see to read and that is my main interest..... But apart from that nothing. Nothing of interest I am afraid. Well the books I could not live without them. I couldn't bear it. I would just be driven crackers." (interview 2)

During the evenings her activity changed. She listened to the wireless or the television. These daily activities provided a framework for other events that took place during the week. Two were particularly significant to Anne. First, she looked forward to Thursday evenings when her long-term friend visited. During their *"get togethers"* they discussed ongoing events in their life and shared supper whilst enjoying some form of entertainment:

"On a Thursday night when my friend comes we watch the TV together, as she likes her Emmerdale and Who Wants To Be A Millionaire..... I like that one also. We chat and she says oh you have won such and such, and I go alright and I have £500 - shall we half it. Get to the £1,000. That's £500 each we've got. Silly old biddies. But it is a good programme." (interview 3)

These times were reminiscent of the "*Nights-in"* she had enjoyed with family and friends in her own home. The second was the weekly phone call from her son. During these calls she received updates of the happenings in the family's life and she kept them informed of her circumstances. It was extremely upsetting and frustrating when the telephone systems in the home caused difficulties in receiving these calls. Whilst the staff were aware of the problem, she felt that the repairs would never be accomplished.

These routines set the pattern for much of her life, so her life was predictable. She really welcomed the times when the routines were changed by events that she wanted to happen. When her son indicated that he intended to visit, for example, there were months of preparation. During the calls leading up to the visit there were plans to be made and much to talk about. Her days were busy as she considered the details of the visit. There was a freshness in their exchanges and great anticipation of the visit. She described her reaction to this time as the "*Cheshire cat grin could not be wiped away*". The knowledge

of his pending visit dominated her thoughts. The visit itself was initially difficult because there had been such a "*passage of time*" since they had last met and "*it was difficult to get a conversation going at first*". This quickly passed with the face-to-face encounter resulting in great pleasure. The parting was sad but it was quickly followed by on-going telephone calls.

Ongoing contact with family and friends maintained continuity in her life throughout the changes that she had experienced in her living circumstances. Amidst the meetings, routines and events that Anne spoke of, she referred to the minutiae of daily life. This was centred around the encounters that she had with other residents and staff.

Relating to others in the home

The resident community: Since moving to the home she found that her interaction with other residents had become increasingly limited. This seemed to stem from two factors. First, her visual problems limited her ability to sustain relationships with other residents beyond a very brief encounter. She had difficulty recognising people and she felt that other residents often attributed this to rudeness. Secondly, many of the other residents had communication difficulties and this limited discourse:

> *"I used to go down to the sitting room which is beautifully decorated with lovely armchairs and lovely furnishings and photographs. Really nice you couldn't get it more homely. They keep changing things around which makes things worse for me. Never mind. They* (the staff) *will introduce me to somebody and I can sit and talk with them for a little while, not very long. I can't always understand what they are saying. And the next day, I wheel myself straight past them and they think, she's a bit stuck up there. And they don't speak to me and I don't speak to them. We are like bits of kids, oh dear God. To think that I have come to this. I have been talking to a woman for ages and the next day I wheel myself past her because I cannot see her and I don't recognize her."* (interview 1)

In her daily life she faced continual embarrassment because she was aware that she continuously breached social conventions when she failed to acknowledge others following initial introductions and discussions. In

response she avoided contact with other residents and spent a large proportion of her time in social isolation. She did, however, maintain her interest in her fellow residents. From the privacy of her room she could hear their conversations and what they were doing:

> *"They are in the background, you hear about their relatives and you listen to their conversations when they are walking up and down - they are just acquaintances."* (interview 8)

These background encounters were important as part of the general milieu of the home and listening to them added an additional dimension to her life.

The staff community: Anne invested much personal effort in developing relationships with staff - she attempted to remember their names, personal details and interests. She felt that she had developed close relationships with some staff and had shared mutually enjoyable times with them. Here she describes her friendship with one staff member:

> *"Oh I had every faith in her. Every faith she could have taken me anywhere and I would have gone. You don't meet many people in life like that and know so early on in the relationship..... I might take years to get to that stage with somebody else but with her it was just natural from the beginning. Just natural she would talk about her family and she wanted to know all about mine. What made them go to Australasia and all the rest of it. So sympathetic when I told her about my sister dying out there. So sympathetic and not sloppy sympathetic."* (interview 7)

She had developed a similar type of relationship with a few other people, but the majority of her interaction with staff was more of a functional nature - they performed the task that was required and had little time to chat:

> *"? was a nice young lass. But she always was in a hurry - too much in a hurry. She always wanted to get away and getting on with probably more important work. At least that was the impression I got."* (interview 7)

Talking to other people was immensely important to her - through talk she was able to tell of herself and in this way she retained her identity as a person rather than existing as a mere object of care in the home. As the transience of

staff in the home increased, her relationships with staff became more functional. In some situations, staff worked in the home for such a short period of time that she didn't even have time to get to know their names. This had a marked impact on her, and at times she felt ill at ease in the home. She felt:

> *"Very upset. You never know who is going to walk through the door when you wake up in the morning and when they bring your breakfast in. You ask their name and you ask that half a dozen times during the day because you have forgotten and the next thing you know they have gone and they don't even say goodbye - they just disappear."* (interview 7)

When talking about what made her feel more or less comfortable in the home she referred to the lack of time available to "*have a chat*" with staff to get to know them, and the perpetual turnover that led to a lack of continuity making the home feel less home-like.

The biographical significance of care

For Anne moving to a care home was a way of maintaining her independence in what was becoming a dependent life. She vehemently resisted the idea of being increasingly supported by family and friends. Whilst she actively sought to maintain her contact with these people she wanted to retain her relationship with them as one of mutual reciprocity rather than one of dependence on them for care and support.

In the care home she was supported by staff to follow her interests. As her abilities deteriorated, she sought different ways of seeking stimulation and pleasure. This became increasingly difficult as the opportunities to do this narrowed, so she turned her attention to developing close relationships with different members of staff - knowing about their personal lives, their interests and their difficulties. The quick turnover of staff in recent months had made this difficult. This caused Anne much sadness - not so much for the loss of friendships but more concerning the loss of opportunities to enjoy the companionship of others. Her birds, bought by a member of staff, became her

constant companions as the opportunity to develop close relationships with other people became more restricted with the passage of time.

Summary

Anne had suffered from chronic, debilitating back problems for many years prior to making the decision to move to a care home. Following the move she was supported by care staff and friends to shape a life within the home that enabled her to pursue her interests. She particularly valued being able to sustain her relationships with long-term friends. As her physical condition and vision deteriorated she withdrew to her private room and lived in social isolation from the care home community. A few activities and regular visitors provided her only stimulation from the same routines. The home, once a haven of independence for her, had in recent times become a place where she received care through prescribed daily routines.

2: Case reconstruction: Beatrice

Getting to know Beatrice

Being a devoted wife and homemaker was the way that Beatrice described her earlier life. Her early adult years were centred around meeting the needs of her husband. Although they had longed to have a child, this never happened. One response to this situation was the considerable attention that she gave to her extended family, particularly to her nieces and nephews.

Following her husband's death, more than thirty years ago, she continued to live an active independent life. She focused her attention on participation in church activities as well as maintaining her involvement with her family. She continued to live in her marital home, a place that held so many memories for her. When she could no longer manage her home she made the decision to move to a sheltered housing complex. In this setting she pursued her interests, indeed her network of friendships and range of activities increased.

The stroke changed everything that she had known - the hemiplegia left her with her an inability to move the left side of her body. Following this, she was told that she could no longer live in the sheltered housing complex and needed to move to a nursing home. Since moving to the nursing home her life was characterized by dependence on others to assist her with every aspect of living, loss of relationships based on mutual reciprocity and loss of ability to customise her lived environment. When data collection commenced she had lived in the nursing home for two years.

Life as a resident: Time standing still

Daily life was prescribed for Beatrice through the routines of the home. There was little diversity in her activities and the company that she kept. Time and again she spoke of the unchanging pattern of her life:

> *"I get woke up, well I wake myself up about 6 o'clock and then they come and dress me and I go for my breakfast. I have breakfast and I am all spick and span by 9.30am. Then we sit in there* (in the public lounge). *Well I never used to look at television, but I know everything now on television. Oh, these box things, Emmerdale Farm, oh I never used to look at those. I used to read a lot, but you cannot do that when people are chattering. I cannot concentrate; it was very hard at first. You cannot concentrate talking to anyone.....oh it used to wear me out just talking to people. I talk more now than I have ever talked, eeh."*
>
> (interview 1)

Beatrice felt that this routine was only broken up by group outings from the home. Whilst the days turned into weeks she found that *"Time stands still. It does, it stands still"* in the home. Even when she attempted to alter the routine, her limited mobility and lack of support by others restricted her ability to do so. This was highlighted in the sixth interview when she spoke of her desire to watch the end of a football match that was being played between her team and a strong rival. During the second half of the match a member of staff entered the lounge and turned the television station over without consulting the residents who were in the room. This was a great disappointment to Beatrice and the other residents but they did not challenge the actions of that member of staff.

She felt that she had little control over her environment and what happened to her. Even very personal decisions about the time she got out of bed in the morning and the clothes that she wore were made by the staff:

> *"They put things on me and I haven't seen them for months and months. I don't know where they get them from. One day you have a vest on and the next day you haven't. I had no vest on today. She was just going to put my blouse on and I said, 'Oh I have to have something on inside my blouse, you can see right through this.' 'Oh come on Mrs. You are not that modest,' she says. 'I said it is not being modest it is being, I don't want to get cold.' So she had to look through the drawers."*
>
> (interview 2)

So she focused her attention on what she could do, such as modifying the space around her wheelchair. For example, when she received flowers from her family she placed them on "*my sill beside my seat*" rather than putting them in her room. With the stroke she lost the ability to move and to do things for herself. She was able to make decisions, yet needed support to carry out those decisions. This led her to challenge the views and actions of staff, and through her persistence she managed to exert some control over her life.

Relating to others in the home

The resident community: Beatrice's close contact with the same group of residents day after day resulted in her having in-depth knowledge of their family, friends, personal circumstances and their behaviours. Whilst this intimate contact with a small group of people led to an understanding of each other, it also resulted in conflict and aggravation as portrayed here:

> *"Well she says 'I don't know why you always have to do that?' Well I says 'Alright I will say yes and no!' I says, 'In fact I am not going to say anything. I m not going to say another word.' 'Thank goodness,' she says – 'Right oh okay I'll remember.' We go away - when we go away and when we see each other again - she'll look at me as if to say are you still speaking to me? I say 'Good morning,' and then she will smile. You couldn't get vexed with her but she has said some awful things. She said get off my back one day. I said 'I will,' and she says 'You will be sorry.' I said, 'I won't be sorry.' I said, 'Well we will wait and see.' But she says things out straight - she is too straight in fact."* (interview 7)

Throughout her discussions concerning interaction with other residents she indicated that the main disadvantage of living in the home was having to put up with the behaviours of other residents and interferences from them, as described in this story:

> *"And oh we got on the table with this person. She's in here and we all play war about her - she should be told about it really. She drinks your tea and eats your food. I had no tea she drank both my cups of tea..... she should be told. Or she should be sat at a table where she can't do things like that. You see the first time she sat at my table I didn't know about it. She picked my cup up and I said, 'No that's not yours'. I said, 'That is mine,' and everybody on the table looked at me as much to say what do you think you are doing - let her have it. But I didn't I just drank. And she gets her cup and she pushes it nearer to yours and as she is getting nearer to your cup. Oh she is cute. She is getting nearer to your cup even if your cup is in the middle of the table she gets out and pulls it in. She pushes her cup besides your cup so that is why when her cup is finished she can get your cup."* (interview 7)

Although she found interacting with other residents largely unpleasant, she knew that she would spend a large proportion of everyday with them. The greatest amount of time was spent with those who frequented the lounge. Over time she roused their enthusiasm to participate in group activities. By enlisting the support of relatives she organised games of dominoes. In this way she attempted to fill in the time with something that provoked the type of interaction that was acceptable to her.

The staff community: Beatrice is an observer of the staff community - they are the carers and she is one of the cared-for. She observed their behaviours and what they did when they worked in the home. She knew their skills and their preferences. For example, she knew the people that they liked to work with. Apart from this type of information she knew very little about them.

Although she felt that she had little control in the home, this did not stop her challenging the actions of staff, as illustrated in the story that she told about the vest (see p.127). She also supported other residents to challenge practices in the care home by using the home structures to bring about change as described here:

"Tell them what you want. You create war about sitting here waiting for your tea. I said well tell them. And she did. She said 'Beatrice do you know what I did…I spoke up in the committee.' And I said good for you, what did you say? She said 'I told them that the tea was no good…..it was cold when it got to us'……..so they started making the tea in the same room and they've got tea pots now…and its more like tea."
(interview 3)

It is only when the staff got to know her needs and her preferences that she felt that she was receiving the best care. She felt that the high staff turnover in the home impeded this. When she became aware of members of staff leaving the home she was saddened because it:

"meant that time had to be taken for them (the new staff) *and residents to get to know each other. It was important that that they* (the staff) *knew what she needed and how to help her."* (interview 6)

The biographical significance of care

The nursing home was a place where Beatrice's physical needs were met. She acknowledged that she was unable to physically care for herself and that she was now dependent on the assistance of others. Whilst she thrived physically; emotionally and socially she felt that she was slowly dying. She had little choice over how she lived her life and she had to put up with situations that she found less than desirable and sometimes extremely unpleasant. Most of her days were spent in the company of others, but she felt lonely. In the confines of her own room she was unable to do anything that she enjoyed - she even felt robbed of the pleasure of looking at her possessions as many belongings were given away when she moved to the home.

Summary

Beatrice chose to move to sheltered housing when she could no longer manage her home. She enjoyed living there. Following the stroke, she was informed that she had to move to a nursing home, so she reluctantly moved

there. In the home her days were filled with activities centred around her physical needs and she longed to do things that would fill the void she experienced. Her life had changed from independence to dependence, and meaningful activity to one of inactivity. She could see the days turning into weeks, months, and then years, yet it was as if time had stood still for her.

Care home B where Charles and Doris live

Care Home B

Care home B was a dual residential/nursing home that was registered to provide 40 resident placements. Within the specified placements the home provided specialist convalescent care for those over 55 years. Ten men and 28 women were living in the home at the time of data collection.

The home was purpose-built by a small provider company that operated in the North-East of England. It was located on the main road of a suburb of a large urban area. There were shops opposite the home, which included grocery stores, a newsagent and a post office. As the home had a central location it was a facility that was well known to local people. The location made the home convenient for people to visit frequently, even if this was for a quick chat as illustrated by the following story:

> *"They* [the residents] *can be sitting on the patio in the summer and they'll call over to someone that they know who is popping into the shops. There is one lady who sees her son going to the club that is across the road. And he will come over and sit with his dogs on the patio.....A lot of people come over from the club and chat."*
>
> (Manager)

This home was similar in design and facilities to Care Home A. On the lower floor the lounge area had large windows and a patio area that faced onto the main road. This enabled the residents to observe the comings and goings of the local community, which promoted much discussion between the residents.

The care staff provided personal, social and nursing care for the residents through team and key worker systems. Although there was movement of staff between the teams, the staff attempted to work mainly in one team to promote continuity for the residents. The low turnover of staff also enhanced continuity in the home. These factors enabled the staff to get to know the residents, their needs, their preferences and their idiosyncrasies. With this knowledge they were able to build up a good rapport with residents and respond to them in personalised ways. The staff suggested that these facets of the home combined to create a "*nice atmosphere*" that was home-like. In the following quotation two carers discuss the importance of knowing the residents and basing their interaction on this:

> Carer 1: *"Everyone is different. We know how to speak to one resident maybe differently to another resident, you know what I mean?"*
> Carer 2: *"Like laughing and joking on with one?"*
> Carer 1: *"Yeah! You might do that, but maybe with someone else you can't do that."*
>
> (Care assistants)

Many of the staff lived in the same locality as the home. This promoted communication between staff and residents and in some cases familiarity through shared experiences:

> *"Well some of the people in here I know because I live in* (this suburb)*. And there have been some people that I knew as I was their home help prior to being a carer here."*
>
> (Care assistant)

The staff aimed to create "*a community within the care home that existed within the wider community*". They attempted to do this by staging community events in the home, such as summer fairs, *'pea and pie'* suppers and church services throughout the year. The residents were encouraged to take part in planning and participating in these events. By holding these activities in the home there was an ongoing exchange between the external and internal communities, rather than the care home being a closed institution within the locality.

3: Case reconstruction: Charles

Getting to know Charles

"*I have been lucky all of my life,*" epitomised Charles' view of his life. He enjoyed a satisfying career initially as a barber, and later extending this to running his own barber's business from his family home. He was an established member of his local community as he worked there for most of his life, apart from the short time that he spent abroad in the Royal Corps of Signals. When his sight deteriorated following a detached retina he made the decision to take early retirement due to ill-health.

As a bachelor he had been able to pursue an active social life when he was not at work. In his earlier life he had been a keen cyclist, which led him to travel extensively with his friends throughout the North-East of England. As he grew older and his abilities changed his interests also changed. And so he moved from cycling, to walking and onto golf. With each of these new interests he extended his social network and added to his group of life-long friends.

Whilst he had faced many transitions throughout his life, the loss of his left-leg, through an amputation, required the most significant physical and emotional adjustments. He was offered a community care package to support him to live in his own home but he decided to move to a care home. He selected the home that he wanted to live in, which was located in the heart of the community that he knew and loved. Following the move to the home he remained optimistic that he could lead a fulfilling and satisfying life. He organized his extensive network of friends into a regular flow of visitors and helpers to assist him to attend nights out from the home. When alone, he focused his attention on the interests that he pursued within the care home. He has now lived in the home for six years.

Life as a resident: rethinking personal satisfaction

During the various stages of his life Charles found that he had to adapt to many different circumstances, and he found that having a positive attitude and looking for the best in every situation led to satisfying outcomes for him. He felt that he needed to approach the life style change that he experienced following the amputation in the same way. He quickly realized that his whole life had changed and when he evaluated his situation he felt that the move to a care home would enable him to be more independent than becoming a *"prisoner in my own home".*

He quickly learned that the routines of the home centred around the mealtimes and he used this as a framework to develop a pattern of life that was to his own liking:

> *"I have breakfast and after my breakfast I go down stairs to about 10.30....and then I just have a look around to see if everybody is working alright and keep my eye on things...oh they keep on saying if there was a union around here I would be the shop steward. And then I am back here about 10.30am ready for my 11.00am cup of tea and whatever. And then I get ready for my daily newspaper* (an audio-taped newspaper)... *from* (the local town). *I get it about 4 times per week so I get to know what is generally going on. I have heard most of the news on the TV you know, but it fills in half an hour or so. And then I go downstairs and talk to a bloke downstairs till about 12.00pm and then it's dinnertime. That is my morning. Well afternoons. Well invariably I have someone in so that is that. Then in the evening it is TV time except on a Tuesday night. I go out on a Tuesday night."* (interview 2)

Throughout the week, during the afternoons, he had a regular flow of visits from family and friends. He attributed his success in maintaining a high level of contact with family and long-term friends to the location and accessibility of the home. Charles valued these regular visits as they provided a link to his past and a way of interacting with people who shared his interests. A special feature of his long-term friendships was the way that these people committed themselves to providing transport to enable him to enjoy some time out of the care home:

"I have 2 pals and they visit me twice every week....and on a Tuesday night one of them comes and picks me up and we go for a couple of pints That is what you call friends, twice a week except when they are on holidays and that sort of thing. But twice a week that is 6 years on a Tuesday night.....that's the kind of friends that I have had all of my life."
(interview 1)

Amidst the routines of the home and time with friends and family, Charles endeavoured to develop new interests that fitted in with his new life style. Throughout his life he changed his interests when his abilities changed and this was no different. In his own room he created his own entertainment suite, which included a television, talking books, radio and hi-fi system. When alone, he was able to follow lifetime interests, which included reading biographies and examining contemporary issues. Thus, he had an active private and public life within the confines of the care home.

Relating to others in the home

The resident community: Charles felt that he got on well with other residents. He was well known to everyone as *"I am the chief carrier* (of news)", thereby being a crucial link in the informal grape-vine of communication that existed between residents and their visitors to the home. He had earned this accolade because of he was a good listener, a good communicator, willing to strike up a conversation with others in the home, and interested in people.In his interaction with his fellow residents he considered that he rarely developed the relationship further than the superficial exchange of information because the majority of the other residents had communication problems and were unable to enter into an extensive conversation:

"I am about the only one here that can speak. Unfortunately everybody else has had a stroke and their speech is a bit affected...It is really difficult when there is nobody that you can converse with except for the people who come to see you... I know everybody here but there is nobody that I can go and talk to."
Researcher: *"Yes."*
"Nobody, there is a couple of people downstairs that I go and talk to. Well I understand only half of what they say." (interview 2)

He would have welcomed the opportunity to develop close relationships with

other residents. However, he found that the resident community had been drawn together not out of mutual interest but of their need for care. This minimised the possibility of developing friendships in the home and he continued to devote his energy and the "*little precious time that he had left*" to sustaining the close relationships that he had developed throughout his life:

> *"You are not forced to mix. It is just as well because I haven't anything in common with these* (residents) *as far as I can make out. I am just as happy to be on my own and see my friends when they call."*
>
> (interview 4)

The staff community: Generally, Charles felt that he got on well with the staff and he enjoyed talking with them. Being a well-known figure in the local community often resulted in Charles knowing other people that the staff also knew, and this provided a connection and a subject that was of mutual interest. He valued these types of discussions because they provided an opportunity to talk with staff as an equal. In the same way, he also enjoyed discussing current affairs with them as he had an extensive knowledge of this subject. He preferred this type of social interaction when he had a detailed conversation with another interested person.

He has known some of the staff since he moved to the home. With the passage of time and regular contact he got to know the staff in a more personal way. This formed the foundation for their relationship to develop from social interaction to a comfortable intimacy.

> *"You get to know the staff and the staff get to know you and you get to know who you can kid and joke with and who you can't."*
>
> (interview 2)

When they were missing from the home, either ill or on leave, he was concerned for their welfare:

> *"I don't like to see her off she is such a nice woman. I always have a bit of chat with her sometime during the day. I don't like to see her off with the angina because the next thing is it could be heart trouble……I wouldn't like to see her have to pack the job in."* (interview 4)

The biographical significance of care

For Charles, the care home provided a place where he was assisted to do the things that he could no longer do for himself and it was a place where he was supported to live the life that he chose within his physical restrictions. He was happy with his choice of care home. It was located within the community where he had lived throughout his life. Importantly this enabled him to maintain contact with family and long-term friends. Being able to make this connection with his past was important to him as it provided one way for him to experience continuity in his life.

Though he lived in the care home with other older people there were only a few people that he could interact with. The majority of residents were unable to engage in conversation as a result of communication and/or cognitive problems. He addressed this by participating in daily events in the home and by developing activities that he found fulfilling.

Summary

Throughout his life Charles had always strived to be satisfied in all circumstances. Following the amputation of his leg he made a pragmatic decision to move to a setting where he was able to reconstruct his life and access the care that he needed. He was no longer able to engage in the physical activities that he had previously enjoyed, so he turned his attention to other interests. As a resident he took the opportunity to revisit his childhood passion of reading (auto)biographies and studying contemporary events. His life as a resident revolved around these activities and the regular visits and outings with his network of long-term friends.

4: Case reconstruction: Doris

Getting to know Doris

Doris' early adult years were focused on supporting her family. The years during the Second World War were hard times and the family survived by working together. She made her contribution by working in the armaments factory. After nine years of this heavy work she left the factory to take a position as a barmaid, where she met her husband. This was an "*unhappy marriage*", which ended quickly with Doris nursing him until he died. From then onwards she lived alone, devoting her time to maintaining her home and enjoying the company of her friends. Now these times were distant memories as all of the people who had been close to her had now died.

As her age advanced her nephew visited regularly and helped with the major decorating of her home, otherwise she indicated that she "*managed quite well*" in her own home. This changed with the stroke. After a period of rehabilitation it became evident that she was no longer able to self-care. When she was asked to consider moving from her home, a place that represented her memories and was full of her personal treasures, to go to a place where the appropriate type of care was available to her, she was saddened. She agreed to a trial placement in a nursing care home and after this she decided to stay.

After moving to the home she continued to regain her ability to walk, and to care for herself. Now she is quite independent and needs little care, but she is unable to leave the care home because her house and her possessions have been disposed of. As she has become acquainted with the other residents she enjoys their companionship. She has now lived in the home for one and a half years.

Life as a resident: enjoying companionship in later life

The move to the care home entailed a complete change in lifestyle for Doris. At first life centred around the routines of care, however as her physical

abilities improved she developed a life focused around the rhythms of the home. This involved the patterns of daily activities, such as mealtimes, and the constant interaction with those living and working in the home. From her waking hours she was aware that others were nearby:

> *"Life is altogether different from being in your own home...I am up earlier. Well from about 6.00am. In my own home I would have been up around 9.30am."*
> Researcher: *"Oh what causes you to wake up? Do people come in and wake you up?"*
> *"No, you hear them starting."* (interview 2)

Some people may have been irritated by this type of background noise, but Doris welcomed it. The continual presence of others contrasted positively with the lonely life that she had lived at home. She went further than merely living with the presence of others - she developed activities and routines that ensured that she was involved with the staff and other residents. Most mornings she sat in the foyer to let the staff into the home as they arrived for the early shift. This provided the opportunity to find out who was working in the home that morning and to have a quick chat with them.

Later in the day she frequented the main lounge where residents met. Here they chatted, watched television or took part in group activities like 'housy'. These activities were regularly interrupted by the programme of weekly entertainment that was announced on the notice-board in the foyer. She was an eager participant of these events.

Whilst her life was full of activities that she found enjoyable, she longed to participate in something that was useful. Prior to moving to the home she was a keen homemaker, and in this setting everything was done for her:

> *"I have always worked and I didn't sit down when I was in my home. I was always wanting to be doing something to make it better."* (interview 5)

She wanted to do the dusting or some other type of housework in the home but she was aware that she would be unable to do this as she no longer had the dexterity or the physical abilities to do this. Creating her life in the home meant that she moved away from physical activities to engage in mainly social activities.

Relating to others in the home

The resident community: Doris quickly became acquainted with many of the other residents. She knew their background, their preferences and mannerisms. She found, however, that getting to know some residents wasn't an easy process. Some people readily entered into a conversation whereas others were more reluctant to do so. At first she felt insulted when others failed to interact with her. After living in the home for some time, she developed strategies for these different encounters. She had responses for times when others wanted to interact with her, and responses for situations when they were quiet and appearing to ignore her:

> *"Well I am one who can't throw myself onto people. If they don't speak to me that it is it you know. I sort of keep myself to myself. But I am as happy as the next one."* (interview 2)

Of all the residents who lived in the home, she knew the residents who came to the lounge and those who took part in the communal activities most. These people had become her companions and she enjoyed being with them:

> *"I used to live on my own you know. I have always liked company. When I was younger I always went to dances and I have always liked to be among people. But I have my likes and dislikes, but it is a funny thing to say for sure but I am really happy when I am amongst people. I hadn't realized but I must admit the truth to myself because it is that I am happy among people and I am not on my own."* (interview 1)

Sometimes these people irritated each other and this resulted in arguments. As a group they had become attuned to each others moods so when they first met each other in the morning they could assess how the day would go:

"I suppose everybody doesn't get on with everybody you know. Well I mean I am sure it is not everybody....some days people are in a good mood and you can joke.....(when they are in a good mood) *they are being nice to you and that is the bottom of it. I mean if anybody is nice to you it brightens you up but if they are not nice and they are having a niggle at you that upsets you."* (interview 2)

When Doris felt that the mood was low she retreated to the solace of her room. She did little more than sit on her bed because she had little confidence to turn her stereo on but at least she had a retreat to go to when she wanted. If she felt lonely she sat in the foyer of the home watching the staff and visitors come and go. Her ability to walk independently gave her choices about interacting with others and this was important to her. Generally they enjoyed being together, taking part in activities that filled their days in a pleasant and satisfying way.

The staff community: During the day Doris watched the staff as they came and went. Their days appeared to be hectic ones. She believed that there was a necessity to get things done at the right time, as this had been impressed upon her early in her career so she ensured that she did not interrupt their routines. Her observations led her to appraise their actions and their work. She spoke highly of some staff:

"Oh she is a good worker. Her and J. stott around this place. They are marvellous." (interview 4)

If their work failed to gain her approval she let them know. Occasionally she mentioned her concerns to the matron as she felt that this is the appropriate action and not because she was a "*tell-tale*." In the following story she told a story about a situation where she disapproved of the actions of a carer and the consequences of her intervention:

"Well this girl, I was sitting here and one of the girls was talking to me and this girl passed by and she said 'oh you be careful what you are saying.' I said 'Who do you think that you are talking to?' I said 'Mind you're own business, you were listening there and you had no call

listening at my door.'.....I told her off and she went off in a huff pushing the chair. And she was in the other day and that was the first time since I told her off. I never looked at her. I mean I could see her but I never spoke to her or anything." (interview 5)

Her relationship with the staff extended further than observing and evaluating their work. She got on well with the majority of staff. She suggested that they were "*friendly and nice people*" that she tried to enter into meaningful interaction with. She felt comfortable in their presence and she liked to be around them. She was able to confide with these people and this was another aspect of life that she valued in the home.

The biographical significance of care

Doris had lived alone and had been very independent for most of her adult life. She engaged in different activities and she had been happy with the life-style that she had set for herself. When she collapsed, believing that she was dying, the fear of being alone, particularly if the same thing happened again, overcame her. The move to the care home was symbolic - it was a place of refuge where there were always people around, so she knew that she would not die alone.

Following the move to the home she established a new way of life. She had left behind familiar routines and her home, and had entered a place where life was vibrant and ever changing. People lived and worked in this setting and she found that the social world, that started to close down in her own home, had opened up again in this new environment.

Summary

Doris moved to the care home following hospitalisation after she had a stroke. Though she had regained some abilities with rehabilitation, her recovery was slow. Her mobility continued to improve when she had moved to the home and a year later she was fully mobile and quite independent. In the care home she enjoyed the companionship of a small group of people and through

constant interaction with them their relationship developed. She enjoyed being with them and taking part in communal activities. For Doris life as a care home resident was enriching.

Care home C where Edna and Florence live

Care Home C

Care home C was a dual residential/nursing home registered to provide 78 resident placements (29 residential and 49 nursing). At the time of data collection it was fully occupied with 56 female and 22 male residents. A notable feature of the resident population was that a large proportion were self funding and they moved to the home from a wide geographical area.

The home was located in its own grounds, in a wealthy, inner city area. To the front of the home was a large garden area, and a driveway leading to car parking facilities. Whilst the home had three floors, the facilities were similar to Care Home A. In addition, the home benefited from being part of a small provider company. The staff and residents were able to access resources and services that were provided on a company wide basis. For example, they could book the company minibuses for outings, and staff could access in-house training.

Care was provided through designated team and key worker systems. These approaches worked well because the staffing of the home had experienced little change during the previous five years. Consequently many of the staff knew the residents well and they knew of their experiences in the home - when they first arrived and what had happened in their lives since that time. By working closely and frequently with a particular resident the staff developed knowledge that enabled them to provide personalized care. The manager discusses the importance of this in the home:

> *"It is about the staff getting to know the resident and that takes much longer than writing the care plan and following that through. It is about*

providing personal services for that person to know that they are a valued part of the home and to know that they have got something to give. The staff know the resident and know which residents particularly prefer things. For example, we have one resident who likes Garibaldi biscuits and we make sure that they are on the tea trolley for her.....it is the little things that make the residents feel that you are giving the kind of care that they could have got at home." (Manager)

In addition to management, care and service staff, a designated activities co-coordinator was employed in the home. He met with the residents regularly to explore how they wanted to spend their day and he built a varied social programme from this information. The notice boards bore testimony to the lively programme which included one-to-one relaxation sessions, discussion groups, resident and relative meetings, board games, movie viewings, and fetes. He also spent time with those residents that experienced difficulty in taking part in group activities and sat chatting with them or took them for a walk to neighbouring shops and parks. The function of the social programme was to enable the residents to live full and meaningful lives in the home:

"Really I try to sort of think that this is their home. And really people should be allowed to do more or less what they want do within their home. Obviously there are constraints about their physical abilities but they can still enjoy their life, they can still enjoy life to the full."
(Activities co-coordinator)

The staff felt that this was a happy home where the residents were well cared for and welcoming to outsiders. They encouraged relatives and friends to take part in the events that took place in the home. As a result visitors were constantly coming to and going from the home. This added a dimension to the self-contained community in the care home, which maintained links to the external community and to the social networks that were part of the residents' lives prior to moving to the home.

5: Case reconstruction: Edna

Getting to know Edna

As a young adult Edna moved to London from the North-East of England to participate in society life. This was an exciting time for her that culminated in a

short but unhappy marriage, which ended in a divorce. After recuperating with an aunt in South Africa she returned to England and joined the WRAF as an officer. Her career enabled her to travel extensively. It was only an acute illness that led her to leave the forces and to consider a more sedentary occupation.

As her parents health declined with advancing age, she moved back to her birthplace and became their carer, assisted by her brother. When her parents died she decided to live her retirement in the North-East. When she felt that she was *"getting on a bit"* she decided to move to a sheltered housing complex where assistance was available but she could determine when and what support she needed. Following the amputation of her right leg she was physically dependent on others throughout her daily life, and this influenced her decision to move to a care home that she selected.

After moving to the home she had a stroke that left her further incapacitated - in addition to the mobility problems that she already had, she now had minimal movement in her right arm and expressive aphasia. Now she worries about the possibility that she would suffer further ill-health and the increased dependence that this would bring. Whilst life was restricted by her physical limitations she attempted to make the most of her circumstances and live as independently as possible in the home. She has now lived in the home for four years.

Life as a resident: creating opportunities to be independent

Edna had always cared for herself and did the things that she wanted to do. Her health, however, had failed and she believed that her death was not too far away. Now she required support from the care home staff to do most things. Being so dependent on others was hard for her. In response to this situation she worked within the routines of the care home, to create opportunities to do the things that were important to her.

Early in the morning, prior to the night staff arriving to assist her to get up before they went off duty, she set time aside to say her prayers. Following this she carried out the exercise routine that she had devised to maintain her physical abilities. This involved a series of exercises such as arm raising and hand movements. She had witnessed many residents becoming more dependent on staff as their physical abilities declined and she believed that these exercises would prevent a similar decline. In the following extract she spoke of the policy in the home to move all the residents who required assistance with their meals to one table in the dining room. She feared that this might happen to her in the future because her dexterity appeared to be declining so she worked hard to resist this:

> *"Well Mrs. J. has had to move. I think I may have told you, but she is not so good with her knife and fork and she has gone to another table where they can't manage by themselves."*
> Researcher: *"Who makes those choices about tables?"*
> *"Well the nurses or matron. I am going to have to be very careful because I am beginning to have problems and I don't want to move. I think that I am alright but if you can't do it alone you have to go down on the other table. That of course is sensible."* (interview 4)

After breakfast she returned to her room to catch up with the news by reading her paper, which was delivered to the home, or by listening to the television. The remainder of the day included a range of activities, such as making telephone calls to friends, watching the television, listening to the radio, enjoying the company of a regular schedule of visitors, and taking part in activities in the home. She only attended those events and activities that she wanted to take part in, otherwise she spent her time in her room doing to other things that she had organized.

She felt that being able to make choices about the way that she spent her day was important as she felt that she had some control over what was happening to her. She balanced this with an understanding that there were limits to residents' choices to ensure the smooth running of the home. Mealtimes and the routines of the home were set. The balance between restriction and choice in her daily life is evident in the following account:

"I have breakfast, read and then I have a rest and then lunch. It is far too soon but that is when we have it. I have it in here now and I like that much better. I have never gone in at breakfast time as I had permission. When I came in they said I could have breakfast in my room. I have always had it in here and I like that better. I take my own pills. I keep them all myself. The others get them doled out and I don't like that. Sometimes we have the bingo. We have a very nice quiz. They are very good with the quiz - it is very good indeed. I don't spend much, that is about all that I go to. And then again I read and sleep."

(interview 2)

The above discussion suggests that Edna spent a lot of time in her own room. Since she had the stroke she has difficulty in communicating with other people and this is exacerbated when she speaks for a long period of time. In response she planned her day to ensure that she has time with other people and time for rest.

From the moment of entering her room it is evident that it is a place that is far more than a mere functional space. In this small area she has carefully organized the space to enable her to do as much as she can by herself. A large reclining chair is located near to the patio doors at the far end of the room. From this position she can watch much activity as the patio windows give a good view of the driveway to the home and the front gardens. She has created a pulley system that is attached to these doors and the curtains to enable her to open and close them. This helps her to control the temperature of the room and affords some privacy.

Near to her chair is a space that is full of equipment - table, pens, paper, television, radio, talking book machine, telephone and so on. These were carefully positioned to enable her to use them without assistance. She felt that it was *"nice to sit in"* her room and retreat into her private world away from the hubbub of the home.

Keeping in touch with family and friends had become really difficult so she developed alternative ways to do this. For example, when she spoke to people on the phone she kept the conversation short, also one of the carers

occasionally took dictation to enable her to write letters. These approaches were illustrative of the strategies that she used to shape her life in the home. She acknowledged that her physical and social circumstances were changing, mainly declining or reducing, and she made adjustments to her lifestyle that enabled her to continue to experience fulfilment. The care home staff assisted her to do this.

Relating to others in the home

The resident community: As Edna took part in the daily activities of the home she met her fellow residents. These times provided a formal opportunity to have a chat with other people in a similar way that people meet up with neighbours as they go about their business. Some people are unable to hold a conversation and she acknowledged them through a smile or some other method of non-verbal communication. She found the other residents to be friendly and interesting people:

> *"I am friendly with everybody. I think that is it. I talk to them all. The woman next door* (in the next room) *she is always there..... I see others quite a bit at breakfast time. We talk about things. We talk quite generally. I know Margaret and she is very, very nice."* (interview 3)

Life with other people did, however, have its unpleasant side. The behaviours of some residents disturbed her. They sometimes shouted during the night, resulting in a bad nights sleep, or people were irritating when they behaved inappropriately in public settings. These situations were often excused on the grounds that the person had declining mental health and were no longer in control of their behaviour.

What was felt to be more unpleasant was having features of her bodily functions exposed in public. One example that Edna frequently spoke of was the queue for the hoist. Use of this equipment was necessary to assist her to go to the toilet. The queue was often long so she planned the time that she joined it to ensure that her needs were met. Although she tried to make polite

conversation whilst waiting her turn, this was an embarrassing situation that she endured.

Knowing that others were living beside her was comforting. Edna was helped to interact with other residents by a number of features in the home: the geography of the home resulted in frequent chance encounters with other people; the activities programme brought people with similar interests together; the care policies supported the development of relationships between residents, for example residents were informed when others were unwell, and fellow residents visited each other with a formal invitation in the privacy of their own bedrooms. These factors enabled her to build her social network within the home at a time when her network of friends and family was contracting.

The staff community: Edna was familiar with the matron and team of care staff that worked in her section of the home. Most of the contact that she had with them focused on negotiating or providing the assistance that she needed throughout the day. In the following extract Edna spoke of the ongoing discussions that she had with staff about the trouble she had in staying asleep during the early hours of the morning and their response:

> *"And I get up, get up and go into the dining room in the morning. I much prefer getting up here at 7.00am. Because they can't change my sleeping pills but I have asked if they would you know and I would rather go back the other way* (to the previous medication). *Well the night staff – one of them is very good. She comes and gets me up about 7.00am when she can, she gets me up."* (interview 7)

The continual negotiation of life in the care home required major adjustments for her. Throughout her life she had worked in influential positions where she had been in control of what happened to her. Now she was the cared-for person. Whilst the staff were responsive to her requests, she found that she had to adjust to the situation where she had limited control over the decisions that affected her life:

"It is really difficult. I have had big jobs that were quite responsible….. You have to forget all of that because the carers are, they look after you and if you say something. They have to, well not boss. I can't think of another word but that is I do find, I did quite a long. Well I got used to it but occasionally it irritates." (interview 6)

During the encounters when the staff provided care, she got to know them in a more personal way as they spoke of their background, family and interests. Edna felt that gaining familiarity with the staff through informal conversation was important, because this contributed to the development of a more relaxed, friendly culture in the home. She appreciated the time that the activities coordinator spent with her. She was also acutely aware that other staff were unable to take time to do this because their busy schedule of activities did not allow for this type of interaction.

The biographical significance of care

For Edna, her acceptance of care was her way of gaining the resources that she required to counteract the effect of her declining physical, mental and social abilities. Without these resources she would have been unable to do the things that she found pleasurable. She does, however, struggle to remain as independent as possible whilst accepting the support and assistance she needs to do all sorts of things.

She made adjustments to her lifestyle when circumstances changed that enabled her to continue to do the things that she liked to do. Rather than collapse in the face of the difficult situations that she encountered, she mustered the high degree of self-efficacy that she had always demonstrated throughout her life and she continually reconsidered what she liked to do and how to do it. She persisted to get the best out of her circumstances and continued to look forward rather than live in regret of what she had lost in her later life.

Summary

Edna had enjoyed a varied career and it was not until the amputation of her leg that she decided to move to a care home. Following the move she worked hard to re-create her life. She established ways to maintain contact with family and life-long friends and organised her days around the routines of the care home. This enabled her to pursue her interests as well as engaging in communal activities. Throughout her life she had always been fiercely independent and she strived to maintain her independence as a resident by implementing a range of self-care strategies and modifying her environment.

6: Case reconstruction: Florence

Getting to know Florence

Florence lived a quiet rural community life until she joined the WAF as a short-hand typist and worked for the Churchill Office during the Second World War. During this time she developed a strong friendship with a group of women that was sustained after the war. They had travelled together for business purposes and throughout their lives they continued to do so for pleasure.

She led a carefree existence until her father's health deteriorated. Then she decided to return home to nurse him until he died. After this she did the same for her mother. Following this difficult time she moved to her friend's home in North-East England. For over 25 years they lived as partners focusing on their mutual enjoyment of the arts. Few people understood the nature of their relationship as they felt that they could not openly discuss it. Consequently, when her friend became ill and died she was very lonely. She found many things to do to fill in time but her latter years became little more than an empty existence.

Until her ninth decade she enjoyed good health. The stroke changed this. Following the stroke she could no longer walk or attend to her own needs. She agreed with the doctor's suggestion that she could not live without support and someone to care for her. Reluctantly she agreed to move to the nursing home.

She disliked the dependence that she now experienced in every aspect of her daily life. Though she indicated that the care home staff were competent and kind she did not like their intrusion into her intimate activities. For the first time in her life she had minimal control over when things happened. She had to learn to wait for staff to attend to her and take her turn in the busy life of the home. She has now lived in the home for two and a half years.

Life as a resident: a life of dependency

When Florence moved to the nursing home she bought many personal possessions with her that provided memories of the past in the new place. She felt that she had little choice in the decision to move to the care home, and she was constantly reminded of the circumstances that led to the move from the time that she woke in the morning until she returned to sleep:

> *"I have to have it* (care) *I can't walk. I can't get myself to bed. That one* (her arm) *is paralysed."* (interview 5)

She relied on others to help her to do everything, so there was no aspect of her life that did not come under the scrutiny of others. The practices that took place in the care home constantly enhanced her awareness of this. She was assessed, measured and things done to her. She acknowledged that she needed assistance but she disliked the intrusion that came with nursing care. The following quote portrays her views of care:

> *"They weigh me and they weigh everybody in the home about once a month. It is rather nasty."* (interview 2)

Having to "*wait my turn*" to be attended to added to the indignity of having personal and biological functions on public display. She loathed this aspect of life in the care home. She had never had to wait to fulfil her desires before and this was hard.

Daily life in the home followed a predictable sequence of waking, being attended to, meal times and taking part in activities to "*get through the day*". Although her days were filled with things to do, she felt that they were monotonous. She spent long periods of time in her room watching the TV and listening to talking books. She enjoyed watching the birds that came to the bird table outside of her room and seeing the comings and goings from the home from the vantage of her chair that was set back in her room, giving a good view of the front gardens and driveway of the home.

In the afternoons she took part in the quizzes and the organised social events. Monday, Tuesday and Thursday afternoons were the most significant days of her week. On these days she had paid carers who came to the home to spend three hours with her. Their key function was to take her for walks in the neighbourhood where she had lived and to the cemetery to visit her friend's grave. She looked forward to these days and less so to other days:

> *"I don't get out on a weekend, weekends are miserable. Not miserable, I shouldn't say that. Weekends are very dull. Nobody comes in and there are no visitors. Naturally they are attending to their own things."*
>
> (interview 2)

She particularly disliked wet days as they prevented her from going out. On these days the paid carers tended the garden on the patio outside of her room, managed her bird table, arranged the flowers that had been sent from her family and so on.

Her physical disabilities limited what she could do independently. She took part in the activities of the home as a way to fill in time, whereas the things that she arranged for herself had meaning for her and provided a time for her to be herself. She longed for the time that her existence would end, as this would draw to a close the dependence that she now experienced:

> *"I don't want to live much longer. Not being here. If you had to go to a home yourself you would realize what it is like. It is not that they are unkind. Everything is very good..... I don't like being dependent on other people. Nobody would - you wouldn't like it..... But one has to*

when one is old.....Well I hope I will go any day now. I am 95 you know." (interview 2)

Relating to others in the home

The resident community: Florence had limited contact with her fellow residents. Mealtimes inevitably led to contact with them as they dined together. Until recently she sat on a table with a group of people that she thought were interesting and friendly. They informally chatted over their meals so this was an enjoyable daily routine. When she was moved to another table, by the staff to enable them to assist her with her meals, she found difficulty in communicating with the residents who sat there:

"I sat at a good table once where they were very nice and friendly. We have single tables now. We used to have a long table where everyone sat down. Now we have tables of 4 all over and it depends on the table that you sit on. I have a table with a funny man. A man that talks and I can't understand him. It is sad. It is rather annoying. I will not say anything else.....And that woman opposite me, is asleep most of the time. Very asleep not just dozing as I doze sometimes. And the other one is quite nice. It is not as much fun as before." (interview 2)

She also met other residents when she participated in the group activities. Her decision to take part was driven by her interest in the activity rather than a desire for companionship. She felt that she had little in common with her fellow residents and made minimal effort to get to know them:

"I don't know them and I don't want to get to know them. They all go into the lounge and they have the TV on all of the time which I don't like..... I make the best of it. I have to. I don't see them much as I keep to my room." (interview 2)

The staff community: Florence met the staff when they attended to her needs. They came into her room, quickly doing what was required and then they left. They always seemed to be in a hurry to complete their work, having no time to stop and talk:

"The carers are sometimes a bit off, but that is because they have to hurry (to do their work). *Very quick! Very quickly in the evening especially. I go to bed and that is quite nice."* (interview 4)

Although she spent much time in her bedroom, where she was unable to see what was happening in the home, she was aware that the care staff led busy working lives. There were few of them to care for all of the residents who lived in the home, so they attended residents in turn. This led to situations where Florence had to wait until others were seen before she was attended to.

She felt that the care staff were "*caring and nice*" people who efficiently fulfilled a role that appeared to be a series of tasks. These tasks, assisting residents to get out of bed and providing meals for example, were necessary but they were of minimal importance to her. When she was asked about the things that helped her to feel more or less comfortable in the home she spoke of her desire to talk with the staff when they came into her room or to go out for walks more often:

"I would like to go out a bit more. I go out on a Tuesday afternoon - but I have told you that. It is a Tuesday afternoon only. But the carers would not have the time to take you out." (interview 4)

The care that was provided by the home staff met her physical needs, whereas her need for companionship and for support to do the things that she felt were important to her were unmet. She did not feel that the staff were unkind – the structures in the home did not allow them to give a greater service than what was provided. Though this irritated her, she acknowledged that this provided the backdrop for other types of support that she had organised within the care home.

The biographical significance of care

For Florence the move to the care home was the point in her life when she made the transition from living an independent, active life to one of dependency. With advanced old age and the residual effects of the stroke she had lost control over her bodily functions. In the care home she was sustained. Her physical needs were met. However, she had lost many of the opportunities to do those activities that she found fulfilling.

Had it not been for monetary resources that she used to fund private carers her life would have been reduced to a biological existence. The care home staff helped Florence to organize paid workers who gave her the help and assistance that enabled her to extend her range of activities as a resident throughout the week. Importantly they were instrumental in enabling her to carry out the decisions that she made. In this way she regained some control and meaning in her life.

Summary

Florence had lived an active, independent life until she had a stroke that left her with limited functional ability at 93 years of age. She agreed to move to a care home, but did this reluctantly. In this environment she received care and assistance with daily activities, and this highlighted her dependency on other people. She disliked this and the routines of care that were now part of her life. By paying for private carers she was able to do those things that she enjoyed. This brought release from her daily struggles. Despite her efforts the dependency she experienced increased and she welcomed the end that she believed would come in the near future.

Care home D where Gloria and Harriet live

Care home D

Care home D was registered to provide 40 nursing home placements (including 4 palliative care placements). The home was only partially occupied with 26 residents (18 women and eight men) at the time of data collection. The vacancies were mainly due to the decommissioning of the fourth floor of the home from usage as nursing care beds.

The building was a large, converted terrace house with four floors. The upper floor was now used as a storage area and the two middle floors housed the resident's bedrooms. The facilities in the bedrooms varied. There were en-suite toilet facilities in all of the rooms. However, bathing or shower facilities were only available in some rooms. The views from the rooms also varied. The bedrooms to the front of the home were highly prized by residents as they had large bay windows that looked over the neighbouring park, whereas the rooms to the back of the home were smaller and had a limited view of a back lane. On the ground floor were the service areas of the home and the three communal lounges, which had patio doors that opened out onto the front garden.

When the building opened as a nursing home in the early nineties it was described as "*a lively little community*" that people had their name on the waiting list to move to. At this time the staff worked to provide individualised care, and they strived to foster a sense of community within the home as highlighted by the matron in the following quotation:

> *"it was all about building trust and relationships. We didn't ever treat everybody the same… the residents are not just older people who live in an institution where things are done because they are done and because it is the routine. We tried to respond to everyone as a person who had something to contribute to living together. We tried to support them to take part in their community."* (Matron)

Although the initial residents required nursing care, some were able to walk to the nearby park and shops as the home was located only a short distance

from the busy city centre. Some of these people continue to live in the home. As the years passed, the staff (many of whom have worked in the home for over five years) observed many changes. The most noticeable being the advancement of the average age of the resident population, and with this their frailty increased. Now the majority of residents require assistance with most aspects of their personal care as well as attendance to their nursing needs. With the reduction in the staffing of the home, that resulted from bed-vacancies, there are fewer staff to provide the additional care that is needed.

These changes have had an impact on the social features of the home. At one time the staff indicated that there was a varied activities programme. Now there are very few residents who can independently participate in activities. The majority require one-to-one support to take part in, for example, a game of bingo or chair aerobics. As the staff work tirelessly to meet the physical needs of the residents, this leaves little or no time to organise and carry out activities. Consequently many residents sit in the lounge watching TV, occasionally talking to each other whilst being supervised as a group by a designated member of staff.

7: Case reconstruction: Gloria

Getting to know Gloria

From being very young Gloria was aware that she was very attractive and she took great pride in her personal appearance. Her greatest joy in her early adult years was shopping. She loved to buy clothes that were made from the finest fabrics and ensure that her wardrobe was well co-ordinated with the matching accessories.

She maintained this interest following her marriage, and extended her love of shopping to include buying for her husband and home. Her attention to detail also extended to the care of her husband, so she worked to meet his needs in every way that she could find possible. Her days were filled with routines to

ensure their home was always clean and impeccably decorated and when she spoke of these times she was adamant that she had been very house proud.

Chronic illness, at first arthritis and later Parkinson's disease, prevented her from maintaining the lifestyle of her earlier years. Gradually she was unable to fulfil her role as homemaker. As her physical abilities declined her husband became her carer. She lived a life of chronic ill-health, pain, disability and continual deterioration. With the sudden death of her husband she faced the move to a care home. This was more than a move to care - it represented the loss of the person she loved and the home that she adored.

Since moving to the home her physical condition continued to decline. She is now unable to do most things for herself. When she is able to speak her voice is barely audible. Her ability to move varies - some days are better than others. In addition to all of these problems the pain that she has lived with for so long continues. Now she often thinks of her own death and the release that it will bring. She has now lived in the nursing home for six years.

Life as a resident: Being at the end-of-the-line

Most days in the home were much the same. Gloria was assisted to dress, have her breakfast and then she was taken to the lounge to sit with the other residents until it was time to return to bed. From her seat in the lounge she was unable to see the television that was constantly on, so she watched the other residents and what the staff were doing. Otherwise she dozed for long periods of time. Apart from regular visits from her brother and the occasional visit from nephews and nieces this way of life had become predictable.

The constant inactivity was particularly difficult for Gloria. Over the years, her ability to do the activities that she enjoyed had diminished. She did enjoy social activities, such as meeting her friends for a coffee when shopping and doing craftwork, for example knitting. Now, the inability to walk and being *"too unsteady"* to do even the simplest craftwork had culminated in long days where she passively waited in turn for the carers to tend to her needs. She felt

"*trapped*" in a body that was no longer capable of self-expression and "*fastened in*" the home that she could not leave.

Another predictable feature of her life was the slow progressive decline of her physical abilities and the chronic pain that disease brought. The deterioration in her abilities signified to her that the end was drawing nearer day by day. Until this time came, however, she knew that she would face increasing indignity. Once she was a woman who took great care in her appearance and now she spilled food on her clothes when she ate:

> *"its terrible and I get very depressed about it...I have two painful things that they can't cure.... its all over.. I drop things now and look at my clothes."* (interview 2)

In the home she was under the constant gaze of fellow residents and the staff who witnessed these types of accidents. The emotional pain of these times increased when she required assistance of others with the most personal of bodily functions. Even this did not escape the watchful eye of some residents:

> "Some people may not be my cup of tea. They are too interested in personal issues ..... The other night when John put the teas out this other nosey person yelled at him and told him to put the cups back. In fact she counted how many times I went to the toilet. Although she is charming to other people she is not the same to me. She knows that I don't like her but I do try not to show it." (interview 3)

In the insular environment of the lounge, she lived her life in public. Everyone knew what was happening to everyone else and there was no corner to hide away. This was an uncomfortable situation for her because she was a private person who didn't care to pry into the business of other people. She had lost control in many aspects of her life – the ability to go where she pleased, to attend to her own needs - and now she had lost the ability to choose what others did or did not witness.

The only relief that she had in this situation was the knowledge that she did feel better on some days. When the medication was effective the pain was

tolerable and she had some control over her movement. During these times she was able to chat with the other residents and staff about the normal things in life. These days were becoming fewer as time progressed, again providing a reminder that she was quickly coming to the end of the line.

Relating to others in the home

The resident community: The care home was a place where long periods of time were lived with other people, many of whom were no more than acquaintances. At first she was frightened by the behaviour of some residents because they shouted and appeared to be abusive. Constant contact with them changed her understanding of their behaviour, so she now attributed outbursts or inappropriate actions to their illness or disability:

> *"Oh it* (another resident yelling) *used to frighten me, but now I know that that is just him. He doesn't mean anything by it."* (interview 4)

Gloria indicated that tolerating the behaviours of other residents was an inherent aspect of life in the care home. In some situations, however, it was really difficult to do this. One woman, for instance, always appeared to be competing with her for the attention of the staff. This woman counted the number of times that staff spoke to her, and complained to her if she was attended to first. She felt that the staff were oblivious to the friction that existed between herself and this women, because they often seated her next to this woman in the main lounge.

She had always been a quiet, reserved person who found being in a large group difficult. Now that the advanced Parkinson's disease had affected her speech she was unable to utter more than a whisper, which was virtually inaudible in the noisy communal lounge. Consequently, interacting with other residents was difficult, so she spent much of her time during the day watching others. On good days she made an effort to interact with her fellow residents and the staff encouraged her to do this:

"I get on alright with the people in here - they are all the same. Sometimes I am shy, and they (the staff) *try to get me to join in..... sometimes yes, we play bowls and it exercises my shoulder. I couldn't lie in bed because I would end up in too much pain."* (interview 2)

As Gloria's physical condition deteriorated she spent less and less time interacting with other residents. However, she continued to experience a range of emotions about their presence from dislike to companionship.

The staff community: Gloria felt that the staff were diligent in the care that they provided for her. They watched over her during the day in the lounge and they quickly responded whenever she pressed her buzzer at night for attention. She was particularly fond of the older members of staff who took their time when attending to her and gentle when moving her, with the result that her pain did not increase as a consequence of their actions. They also stopped to talk about whatever was going on in the home. In contrast the younger staff hurriedly completed their task and quickly moved onto the next person. They were not unkind, but they never seemed to have time to talk. This saddened Gloria. Listening, and talking when she was able, were the few pleasures that she continued to enjoy so she welcomed the times that the older staff were with her.

Beyond the few accounts of her interaction with staff, Gloria said very little about those who cared for her. She appeared to know very little about them, yet this seemed to be of little importance to her. They were always there, which was important. She knew that she would become increasingly dependent on them to attend to all of her personal needs, and their actions over the previous 6 years gave her no reason to doubt that they would continue to care for her in the same way until the very end. This was a great comfort to her.

Biographical significance of care

The decision to move to a care home took place in unexpected and sad circumstances. She had anticipated that her husband would care for her until she died but this was not to be. At the time of mourning for her life-long partner she was uprooted from everything that she had known and placed in a strange environment. She had few personal resources left to help her to cope with the move and adjustment to life as a resident. She was unable to do most things for herself so she was very reliant on the staff for their assistance to care for her frail declining body.

For Gloria, the care home was a place where she would progressively deteriorate and a place where she would die. She knew that she would experience increased dependency and further indignities before she reached the end. However, she did not attribute this to the quality of care but to an inherent part of her condition.

Summary

Gloria had suffered from chronic, degenerative conditions since mid-life, which were at an advanced stage when she moved to the care home. Her health continued to deteriorate following the move to the home and she now felt that she was at the end-of-the-line. Most days brought physical discomfort and emotional pain of living as a public spectacle. Though she tried to participate in the community life of the home on her good days, these were becoming few and far between. Her main solace was the knowledge that the staff had and would continue to diligently care for her until the end.

8: Case reconstruction: Harriet

Getting to know Harriet

Harriet felt that her parents had overlooked her. Though she had survived meningitis as a teenager and was determined to overcome the disabilities that

this left, she was expected to work hard serving in the family store. She did this with difficulty - the spasticity in her limbs caused her to be slow and she tired easily. In contrast, her sisters were supported to fulfil their career aspirations, one as a teacher and the other as a seamstress.

Her dissatisfaction with her life changed when she met her husband in her late twenties. Though she continued to work in the store she also took on the roles of wife and homemaker. As she accompanied her husband to the church that he regularly attended, she became acquainted with other members of the fellowship. Developing friendships in this way drew her to participate in a wide range of church activities. These changes in her life were enriching and she felt fulfilled.

The death of her husband saw her return to her mother's house to live with her mother and oldest sister. After this move, Harriet's health slowly and progressively declined. She required more care as time passed, which was first provided by her mother, and later by her sister when their mother died. Later, a stroke left her immobile and further debilitated. Her older sister continued to care for her until she fell one day in front of the living room fire and was badly burnt. This incident created much concern over Harriet's well-being and her two sisters decided that re-locating to a care home would be in her best interests.

Harriet agreed to move to the home, thinking that this was a temporary placement for rehabilitation. Since the move she has continued to deteriorate yet she yearns to return to her own home. She has now lived in the home for three years.

Life as a resident: monotony and frustration

Harriet didn't want to move to the home and she did not like living there. She often speaks of the sadness that she experiences, knowing that she would remain in the home for the foreseeable future:

"well you get so upset when you think you are sort of stuck in here. That is what you cry about. Often I have a few tears." (interview 1)

"I often wish that I could go home. And I cry in bed. I have a little weep. But they say that they cannot manage me at home." (interview 7)

Whilst her material needs were met in the care home - good food, a comfortable private room, toiletries that were bought for her when she ran out, kind staff to give any type of assistance needed - she longed for a different lifestyle. In her own home she was able to do what she wanted. Then her days were filled with meeting friends for a chat and a cup of coffee. Now her days were empty. She got up and joined the other residents in the main lounge, remaining there until meals were served in the dining room or it was time to go to bed. She was *"one of the crowd"* who participated in the monotonous daily routines of the home:

"well there has been nothing to do and that is the worst of this place that there is nothing to do." (interview 1)

She enjoyed the occasions when she stayed up longer than usual. By the early evening the majority of the other residents had gone to bed and the lounge area of the home was quiet. This was the time when she and her companions selected the programme that they wanted to watch on the television and they determined the time that they went to bed:

"I stay up at night. When they have all gone to bed, I and Margaret and Enid stay in the other lounge. We all listen to the television...They (the staff) *don't come and say oh it's time you were in bed, they let you stay up as long as you want..... We just sit and watch the television and enjoy the quietness."* (interview 4)

The only respite from the routines of daily life were provided by visits from her sisters and brother-in-law. Whilst she felt that they had abandoned her to the care home she knew that they made every effort to be with her:

"I think that the most important thing to me is the visiting. I look forward to them (her family) *visiting me. It is such a God send when they open that door and they are there."* (interview 7)

During the visits they did the things that she liked to do. She enjoyed the opportunity to get out of the home, so they took her for walks in the nearby park or the local shopping precinct. In one interview she talked about the time that she asked her sister to get her some wool and knitting needles. Knitting had always been a favourite pastime and she wanted to revisit this. Immediately her sister met her request, and brought in the equipment as she had always done in the past.

Harriet carefully considered how she would grasp the needles but when she was unable to manage to fulfil her plans she experienced immense frustration:

"I could cry now when I think of trying to knit. I had a try. I will try anything once." (interview 3)

She was disappointed - an emotion that was familiar to her. She was particularly distressed over her immobility since the stroke. Being able to walk again was an important personal goal. The professionals had told her that it was highly unlikely that her mobility would improve but she did not believe them. She felt that mobility was the key to her independence. For this reason she competed against a fellow resident to demonstrate to the staff that her movement has improved and she would be able to manage to live on her own:

"I want to be in my own home.....and that is what I am aiming for and that is what I compete with Joan for. She can walk a bit and I can't." (interview 4)

Throughout Harriet's stories she told of what she would like to do and her continual disappointments when she fails to execute her plans. This brought her much sorrow as she strives for those things that appear to be unattainable.

Relating to others in the home

The resident community: The other residents were Harriet's constant companions. She was with them most days from early in the morning until evening. They were always there and she felt that she had no privacy. Their noises and behaviours irritated her. For example, one person shouted constantly and another constantly moved around. Though being able to watch his movements as he wandered provided a source of distraction during the long empty days, Harriet disliked his intrusive behaviour when he sat in a seat that is not 'his'. She felt that it was important to maintain the seating arrangement in the lounge, yet this man appeared to have little understanding of implicit rules such as residents using particular chairs.

Most days she sat next to Gloria in the lounge. This was a fraught relationship. She felt that they had developed a friendship, yet Gloria's actions often lacked warmth and the intimacy that she associated with friendship:

> *"Well she is really the one that I am most friendly with. But at times she is off with me.....she is awful if her brother or relative comes in. She takes them to her chair like this* (demonstrating that she covers her face to hide what they are discussing from others)*...and they talk together nearly in whispers in case you hear anything."* (interview 7)

Harriet experienced a degree of ambivalence in her relationships with the other residents. She desired their friendship and the opportunity to celebrate occasions such as birthdays with them, yet she disliked many of their attitudes and behaviours. She found difficulty in identifying some common ground with these people as they came together out of their need for assistance and care rather than to fulfil mutual interests.

The staff community: Harriet spent many hours everyday with the care staff. They were always present in the lounge, observing and attending to the residents. Though Harriet did not know the names of individual members of staff, other than the name of the matron, she knew of the circumstances and events that were taking place in their lives. When important events happened

in their lives, such as the birth of a baby, she ensured that she celebrated with them by giving a gift or a card.

Though she did not feel that she had developed a close friendship with any member of staff, this was not important. She valued their attentiveness and the kindnesses that they continually showed her. Other than these scant details, Harriet had little more to say about her interaction with the care home staff.

The biographical significance of care

For Harriet, her life in the care home was a life of being detached from the home that she loved. She had no involvement in the decision about moving to the care home and she did not want to live there. After three years of living in the care home she continued to challenge her sister's view that she was unable to care for her safely in her own home. She lived in the hope that she would regain her physical abilities and this would enable her to return to her home. It was unlikely that this would happen as her functional ability had not improved since she had had the stroke. She did not accept this and continued to challenge the opinions of the medical and nursing staff.

Though her physical needs were always met Harriet felt that her life as a resident was empty and monotonous. She tried to introduce new activities that interested her into her daily schedule, and she was supported by her family and the care staff to do this. Often her ambitious plans resulted in failure to achieve the objectives that she had set for herself. Consequently, she faced disappointment again and again.

Summary

Harriet had lived with ill-health and disability since she was a teenager. Yet, she had always been able to achieve her personal objectives and fulfil roles that she had found satisfying. When her abilities deteriorated following the stroke, she continued to experience pleasure by living in her family home and

entertaining visitors. The move to the care home changed all of this. Her main objective – to return to her home – she was continually told was beyond her reach. In response, she set herself tasks to demonstrate to the care staff and her family that her abilities were improving. Time and again she failed in her efforts, resulting in frustration. So she continued to live an empty, monotonous life, as she described it, in the care home.

Conclusion

The lives of the people who took part in the study varied enormously. They were very different prior to their move to the care home and the transition to life as a resident had required considerable adjustment for everyone. Significantly, the differences that were the very essence of their individuality were threatened when they moved to an environment where daily life was structured around care practices and quite rigid routines. They were now a member of a resident community, and this had the potential to limit the way that they could continue to express their personhood in the latter stage of their life.

Yet within this community they worked hard to reconstruct their lives once they had become familiar with the daily rhythm in the home. They drew on their personal resources – physical abilities, coping strategies, social networks, relationships with care staff, financial resources and so on - to do the things that were important to them. In the following chapter it is argued that these were strategies that they used to shape their daily experience of life as a resident. By doing this they were able to experience *'personal satisfaction'* and change *'the sameness of it all'* as a resident.

There were features of the communal environment, such as care practices and living with other people, which impacted on what they could do. Though this subject is returned to in the following chapters, it is important to point out here that some participants were more able than others to shape their lives.

Those who were less able told stories that portrayed their lives as largely focused around biomedical issues that were addressed through the regime of care. They lived *'a life of dependency'* and one that they perceived *'time had stood still'* for them.

The participants' stories were mainly focused on specific events or issues, whereas through the retelling of those stories, for the development of the case reconstructions, the personal narratives that permeated their life as a resident emerged. These narratives, as summarised in the following table, were indicative of their experience and they highlighted the way that older people living in the same care home can and do have very different experiences.

Participant	Narrative descriptors of life as a care home resident
Anne	seeking ways to change the sameness of it all
Beatrice	time standing still
Charles	rethinking personal satisfaction
Doris	enjoying companionship in later life
Edna	creating opportunities to be independent
Florence	a life of dependency
Gloria	at the end-of-the-line
Harriet	monotony and frustration

Table 5.2: Summary of the narrative descriptors of the lives of the participants as residents

Whilst these individual narratives presented different images of life as a resident, they embodied the common experience of living in a care home that they shared with fellow residents. Examining this shared narrative forms the focus of attention in the following chapter to develop an understanding of the individual experience within the wider psychosocial context of care home life.

Chapter 6

Narrative themes within care homes – structural interpretation

Introduction

The idea that residents can live very different lives within a care home, and do so within the same home, was introduced in the previous chapter. Some participants described the way that they lived lives invested with personal meaning. Others lived lives that were focused around biomedical issues that were addressed through the regime of care. The understanding that these differences exist within care homes was derived from a process of re-reading the stories that the participants told. This process focused attention on the way that reference was being consistently made to the same features within care homes.

With this observation the focus of the inquiry moved from the stories told by individual participants to an exploration of the narratives that resonated with their diverse experiences. This process was in line with a tradition that Mischler (1995) referred to as '*told from multiple tellings*', whereby the stories and personal narratives of many people are compared and contrasted to elicit the narratives that pervade the community they live in.

This chapter commences with a presentation of the structural interpretation from the third stage of reading of the narrative interviews that led to an identification of the topics and issues discussed by all of the participants. During this reading four topics were identified, which were:

- moving-in
- settling-in
- living-in
- moving-on from the care home.

These topics were used as an analytic framework to re-examine the narrative interviews and this resulted in the identification of six narrative themes (see p.92-96 for a detailed account of this process). These were narratives about:

- care
- control
- relationships
- personal space
- activity
- having a private life in a public environment.

These are introduced at this point in the thesis and examined in chapter 7.

In keeping with the interpretative spirit of the methodology this examination highlighted the strategies that residents used to construct their experience of each of the narrative themes. In the latter part of this chapter the discussion focuses on the resident's strategies that shaped their experiences of care home life. By focusing explicitly on the decisions and actions of residents, the intention is not to suggest that care home staff, family and friends were inactive in their endeavours to support residents. The intention is to make known the approaches that these people adopted to shape their own lives.

Making sense of the stories that residents told

The stories that the participants told reflected their unique life experiences:

- what happened to them prior to moving to the care home (moving-in)
- the move itself (moving-in)
- adjusting to life in the home (settling-in)
- the way that they re-constructed their life following the move (living-in)
- and the possibility that they would leave the home in the future (moving-on).

By focusing on these phases of care home living the discourses that permeated experiences of moving-in, settling-in, living-in and moving-on were

illuminated. As the analysis progressed these discourses were interpreted as narrative themes which were the researcher's interpretative representation of dimensions of care home life. Different narrative themes were more evident than others in each phase of care home living as highlighted in table 6.1.

The narrative themes were conceptualised by the researcher as being mediated through the actions of individuals. Being mediated through individuals draws on the notion that an individual's experience of the narrative themes is constructed as they work to shape their life in the care home. As such, these themes play out in different ways in the various phases of care home living. The narrative theme of control, for example, concerned involvement in decision-making about the choice or lack of choice of home during moving-in, whereas the focus was primarily on negotiating life-style and care and being supported to execute their preferences during the living-in phase. The following discussion explores what happened to the participants at each of these phases of their life. At the end of each section the narrative themes that permeate the experiences within that life transition are introduced.

Transitions experienced in care home life	**Narrative themes that are constructed and shape a resident's experience within each transition phase of living in a care home**
Moving-in	Narrative theme 1: Caring for oneself / being cared for Narrative theme 2: Being in control / losing control
Settling-in	Narrative theme 2: Being in control / losing control Narrative theme 3: Relating to others / putting up with others Narrative theme 4: Active users and choosers of space / occupying space
Living-in	Narrative theme 1: Caring for oneself / being cared for Narrative theme 2: Being in control / losing control Narrative theme 3: Relating to others / putting up with others Narrative theme 4: Active users and choosers of space / occupying space Narrative theme 5: Engaging in meaningful activity / lacking meaningful activity Narrative theme 6: Living an enriched private life / an impoverished private life
Moving-on	Narrative theme 1: Caring for oneself / being cared for Narrative theme 2: Being in control / losing control Narrative theme 3: Relating to others / putting up with others

Table 6.1: Summary of the narrative themes that are constructed and shape a resident's experience

Moving – in

Prior to moving to the care home all of the participants experienced decreased functional ability as a result of a range of diseases and illnesses. Their physical, functional and cognitive problems contributed to a situation where they were no longer able to care for themselves, and they were dependent on others to meet their personal and health care needs. Following the move, however, Charles did not deteriorate further, and Doris' functional ability, particularly her mobility, had improved. The majority of the participants, however, continued to deteriorate.

How these people arrived in the care home, their preparation for the move and the extent to which they participated in the decision of their long-term living arrangements varied. Charles and Edna assessed their long term living arrangements and the type and level of care that they needed and on the basis of their judgements they made an active decision to move to a care home. Their prior knowledge of the home was highly influential in this decision. Anne was also an active participant in the decision to move to a nursing home. In this situation she exerted what Collopy et al (1991) referred to as '*decisional autonomy*', but she required support in choosing a home. At first Doris had little involvement in the decision to move to the care home. She was informed that she needed to move from the hospital to long-term care in a nursing home, so she agreed to go to a nursing home for '*a trial*'. When the time came to decide whether to stay or move on she was actively involved in the discussions and the decision to remain in the home.

In contrast, Beatrice, Florence, Gloria and Harriet had minimal involvement in the decision to move to a care home and in the choice of home. Others, professionals and relatives, made these decisions for them. Florence and Gloria suggested that others knew best and assented without objection to the decision. Beatrice and Harriet relocated to the care home whilst voicing their objections and highlighting their preference to live in another place. They made their views known but did move to the home reluctantly.

These different levels and types of involvement in decisions to move to a care home have been noted by Reed et al (2003a). These researchers explored the re-location of older people between and within care homes. Their observations led them to conclude that moves to and from care homes are complex and older people are involved in these decisions in different ways. They identified four different patterns of older people participating in such decisions. These were older people who exercised choice (known as preference re-locator); those who planned moves to pre-empt changes in their circumstances (strategic re-locator); those who resisted or disagreed with arguments about their need for care and the limitations of the care provider to meet the resident's needs (reluctant re-locator); and those who had been accepting and unquestioning of decisions of others regarding the level and type of care required (passive re-locator). Similarly, the people in this study had different types of involvement in the decisions about their re-location. The majority had some form of active participation, even if this was to raise their objections to the move, whereas Florence and Gloria seemed to be acquiescent throughout.

Relocation type	Participant involvement in the relocation decision
Preference re-locator	Anne, Charles
Strategic re-locator	Edna
Reluctant re-locator	Beatrice, Harriet
Passive re-locator	Doris, Florence, Gloria

Table 6.2: Participant involvement in the relocation decision

Regardless of the degree of control that the participants had had in the decision to move to a care home, they all made plans about what personal possessions to take with them and what they should give to others or leave behind. Marcoux (2001) argues that this process is a ritualised form of construction of the self through dispersal of belongings and is important part of separation. Even when the move had been well planned, they all described the anxiety that they had experienced when making the actual move. They recalled this as a time when they had faced the unknown. Without exception they had visited someone who had lived in a home and this had left them with

a negative impression of what life would be like in a care home – a time when they would have little control and a time when their infirmity(ies) would dominate what occurred during their waking hours. Their participation in decisions about their long term living arrangements and their initial experiences in the care home were therefore very important in reinforcing or changing the views they already held. Being involved in decision-making and preparation, therefore, were viewed as key factors that influenced whether the outcome of moving-in was perceived as favourable or unfavourable. These findings resonate with the literature that points to the relationship between features of the move to long-term care and post-placement adjustment, with marginalisation from decision-making and absence of preparation tending to result in adverse reactions to the new living arrangements (Chenitz's,1983; Wilson, 1997; Blendin and Riordan, 1998).

Following the move the majority of these people faced an advancement of the diseases that affected them and, with this, increasing frailty. As they became more dependent on home staff to care for them they continued to seek ways to continue to self-care. Edna, for example devised an exercise routine that she believed maintained the dexterity in her hands, thereby enabling her to continue to feed herself (p.145). There came a point for some of the participants where they were very limited in what they could do for themselves and in the main they were reliant on other people to care for them.

Whilst many topics emerged from the participant's discussions about moving into the care home - such a great sense of loss (of their home, social networks and possessions), the fear of dying alone, and the importance of moving to somewhere that they were familiar with - two narrative themes threaded throughout the interviews. These concerned the experience of being dependent on assistance and care from other people, and the way that they strived to continue to care for themselves. The other narrative concerned the extent to which they were able to influence decisions that affected their lives. These narrative themes were:

- Narrative theme 1: Caring for oneself / being cared for

- Narrative theme 2: Being in control / losing control.

Settling-in

The initial days in the care home were a time of uncertainty and anxiety. They had brought to the home many myths concerning what should or should not happen in the home and what they could or could not do. As these people familiarized themselves with their surroundings and the routines of the home they quickly became aware that there was a rhythm to life in the home, which revolved around routines (e.g. mealtimes, visits from family and friends), rituals (e.g. going to bed) and staff shift patterns. In some respects, knowing these patterns provided some comfort during the early days of residential life when they could begin to predict what would happen to them and when it would happen.

Being with other people constantly throughout the day was a new experience that generated a range of emotions, including pleasure, dislike, anxiety and fear. Doris, for example, did not want to move from the hospital, but quickly after moving to the home she found that she enjoyed the company of other residents as illustrated in the following quotation:

> *"He* (the hospital doctor) *said 'I should send you out of here' and I said 'Oh don't!' He said 'Alright.' The next week I saw him coming and I thought well I will lie low. You know, keep sitting back and he found me. He said 'Out you go.' I said 'I cannot, I cannot.'.....(*later when talking about a check-up visit at the hospital and the move to the care home she stated) *You know it is company for me here because I lived on my own."*
>
> (Doris: interview 1)

The participants reacted differently to the move to the home. Some were overwhelmed by the experience of being the centre of unwanted attention and constantly under the gaze of others, even in the most personal of situations. The stories that were re-told of Florence's and Gloria's experiences highlighted their discomfort and their dislike of the constant intrusion of other people in their lives from the moment that they entered the home. Such

reactions to living with others are common and it is at the point of moving into the home that strange behaviour and idiosyncrasies are most evident. They began to develop understanding of the happenings in the home through observing their fellow residents and staff, and interacting with them. Their initial experiences with these people shaped their perceptions of life in the home.

The encouragement to bring their possessions with them, although there were restrictions on the size of the furniture and equipment, was really important. Their possessions were symbolic in the way that they represented their past and a life previously known and cherished. Through displaying their possessions they retained the capacity to express themselves. Here, Florence talks about the possessions that she brought to the home:

> *"This was the only vacant room and I have been here ever since I had to move out of the flat and move all of this out and sell it."*
> Researcher: *"Oh did you?"*
> *"Well I had to as my friend had died and I was on my own. But I had a good niece who came up and helped me and that is all I can say and I have been here ever since."*
> Researcher: *"And you brought your possessions with you?"*
> *"Some of my possessions to make the room look more presentable. That is my very own."*
> Researcher: *"This piece of furniture here?"*
> *"Yes and that* (pointing to the painting on the wall). *That was painted by an aunt and all the others were painted by my brother who was in the air force in the Battle of Britain. He was very talented. He painted that – that was the house where I lived."* (Florence: interview 1)

During later discussions she told stories about the ways that she changed the view that she had from her room through the patio doors. She had always been a keen gardener and with the support of her key worker and her paid carer she developed a patio garden that housed a bird table that was well used by the local wildlife. From the privacy of her room she spent many hours watching something that she had created. It was the encouragement that she was given at the commencement of her life as a resident that signified to her that she was able to create something more than a mere existence in the home.

In contrast, the initial experiences of others led them to conclude that they were powerless to express their individuality in the home. Beatrice, for example, told stories about the first time that she entered her room and she observed her *"things"* being placed in the chest of drawers. Watching these actions of well meaning staff reinforced her perceptions of the nursing home as a place where everything was provided for her – the bed, furniture and care – and everything was done for her. During her initial hours in the home she did have some thoughts about personalizing her room yet these were changed as soon as they entered her mind:

> *"Oh I could but I don't feel like it* (putting her own curtains up in her room). *I have bed linen and everything, curtains. But I was going to ask one of the girls, Sharon, if I could have my own bedspread and curtains to match. But when I came in to the room there were all clean curtains in there and I thought oh that is the end of that then. They are not going to take those down and put other clean ones up when there's extra work for them."* (Beatrice: interview 4)

In her initial encounters with the staff she made assumptions about their actions and their behaviours and this led her to conclude that she could not change the way that things were. She was not told that she could not change her room nor was she told that she could do so. Throughout the process of moving to the home she had voiced her preferences, indicating that she did not want to move to a nursing home and her decision was not acted upon. This had been a disempowering experience that influenced the way she perceived the actions of others in her new home. As she attempted to make sense of the new situation the staff could have shaped her perceptions by informing her of the possibilities for her life in the care home. A lack of communication between Beatrice and the staff only served to increase her feelings of loss of control and vulnerability.

Stanley and Reed (1999), in their book 'Opening up care', discuss the models of care that residents and staff implicitly and explicitly hold. They suggest that three models coexist – practice as benevolence with service users being dependent and grateful for the care that they receive; practice as control where service users lack in agency; and practice as enabling where service

users have the potential for independence. The subtle actions and omissions (e.g. supporting residents to explore what they can do) of staff are powerful indicators to the residents of the models of practice that permeate the climate within a care home. In Beatrice's case both verbal and non-verbal communication, and lack of discussion with care staff reinforced her notion that she lacked control as a resident in a nursing home.

Within the stories that the participants told of their early days in the home, many themes co-exist and intertwine. From these the following narrative themes were identified:

- Narrative theme 2: Being in control / losing control
- Narrative theme 3: Relating to others / putting up with others
- Narrative theme 4: Active users and choosers of space / occupying space

Living-in

A notable feature of all the interviews was the way participants developed multiple levels of existence within the confines of the very public communal environment of the care home. They had their private world of thoughts, actions, interests and close personal relationships, yet there was still a public existence that was dominated by constant contact with others living and working in the home.

The private facets of their lives resulted from meticulous planning and continual negotiation with staff, family and friends. In the reconstructions of Anne's (p.120) and Charles' (p.133) lives as a resident, for example, it is evident that they engaged in a varied programme of activities and visits from friends throughout the week. These times were meaningful to them in contrast to other time-filling activities that occupied much of their day. They spoke of the way that they had organized their schedule to fit into the routines of the home and this ensured that there were times that they could look forward to.

Being able to do this was important to them in limiting the monotony that would have dominated their life.

Being accommodated in single rooms enabled them to experience privacy and it provided a space that they could modify to enable them to do the things that mattered to them. Their rooms had a range of audio-visual equipment that they could use to pursue their interests. Those that had telephones in their rooms were able to contact family and friends, thereby sustaining their interaction with people beyond the boundaries of the home. Some of the participants adapted their private rooms in ways that increased the independence that they experienced in the home. Edna's systems of pulleys and cords to open and close her patio doors without assistance is illustrative of this (see p.146).

Their rooms, therefore, were places where they could develop their world within the home. Kahn's (1999) study, discussed in chapter 2 (p.35) highlighted the importance of having personal space where residents could be themselves within a place that was a safe haven of care. What was notable throughout the stories told in this study was the way that those with physical and mental abilities to make the necessary arrangements to develop their private lives within the home did so, and some of those who were unable to do this without help were given the necessary assistance.

Those who were dependant on the support of the staff for assistance with every aspect of their functioning tended to have a limited private life. Consequently they were more exposed to the more communal aspects of life in the home. Beatrice's description of the unchanging pattern of her life from the moment that she awoke - assisted to get up, dressed and washed to ensure that she was *'spick and span'* for the day, having breakfast, taken to the lounge between meals, and then returning to her room to bed at night - resonated with Lee-Treweek's (1996, 1997) notion of dependant older people being a product of the carer's work. The product being that the resident became *'a lounge-standard individual'* who was presentable to the public world of the care home.

The participants who spent the majority of their waking hours with other people in the public lounge - Beatrice, Gloria and Harriet - felt that they were the focus of unwanted attention. They also felt that they had to '*put up with others*' – the oddities and the strangeness of their behaviors – and this was a stark reminder that they had moved to a very public environment. This did not reflect everyone's experience. Doris relished the presence and company of other people. She did, however, have the ability to move away to the privacy of her own room or to other parts of the home when she wanted a change in companionship. Interacting with other people affected the participants' quality of life in positive and adverse ways. In situations where relationships and companionships developed from being together in the home, their life was enhanced, reflecting the similar accounts that exist in the literature (Patterson, 1995; Kovach and Robinson,1996).

The care home was portrayed by all of the participants as a rich social environment. In addition to interacting with fellow residents, there was contact with the staff. How the residents related to the staff did vary. Some attempted to develop close personal relationships with members of staff, whereas others had a more functional form of contact with them - as the cared-for interacting with their carers. The participants had the impression that the staff were always pressed for time, and although they wanted to share time with them, their interactions tended to be devoted to undertaking the physical activities associated with caring. Much of the research evidence has supported the perceptions that were held by the residents in this study - that being staff prioritizing physical care over emotional support (Armstron-Esther et al, 1994; Nolan 1995). However, the participants wanted someone to share their daily experiences with.

Throughout the discussions of their lives as a resident, the narrative themes changed with the emphasis focused on the way that the individual lived in the care home. Through this analysis two further narratives themes, 5 and 6, were identified:

- Narrative theme 1: Caring for oneself / being cared for

- Narrative theme 2: Being in control / losing control
- Narrative theme 3: Relating to others / putting up with others
- Narrative theme 4: Active users and choosers of space / occupying space
- Narrative theme 5: Engaging in meaningful activity / lacking meaningful activity
- Narrative theme 6: Living an enriched private life / an impoverished private life.

Moving-on

A care home was portrayed as a place where there was constant coming and going amongst those who lived in it. The participants knew of changes within the resident community, yet they had little direct communication with the staff about this:

> *"Oh well it is like the grape-vine as things get round sharp here. Nothing goes round here but like a flash. Everybody knows immediately that there is somebody coming in. You know the moment there are empty rooms and, as soon as anybody comes in everybody will know."* (Charles: interview 2)

There were two ways of moving-on within the care home setting - older people moved from one supportive living environment to another as their needs changed, or they left when they died. The participants had experience of both of these possibilities either through their own situations, or knowing what had happened to fellow residents.

Many of the participants had experienced what Eley and Middleton (1983) described as the continuum of care. As their needs changed with frailty, deteriorating physical and functional ability, they moved on to more intense forms of care. In this sense they moved on from one living arrangement and into another (see table 6.3). In Edna and Beatrice's case they had relocated to a sheltered housing complex in later life, then, following Edna's amputation and Beatrice's stroke, they found themselves in a situation where they were

required to move to another environment that was registered to provide supportive accommodation as well as personal, social and nursing care.

Participant	Participant's movement through the continuum of care
Anne	Home with community care package & periods of hospitalisation – nursing home
Beatrice	Home – sheltered housing – nursing home
Doris	Home – hospital – nursing home
Edna	Home – sheltered housing – nursing home
Florence	Home – nursing home
Gloria	Home – nursing home
Harriet	Home – day care – respite care – nursing home

Table 6.3: Participant's movement through the continuum of care

All of the participants were aware of the possibility of moving-on in the alternative sense. They acknowledged that they were going to die at some point and from something, and it was highly likely that they would die in the care home where they were now living. This reflected the picture that is emerging within the literature, of substantial and ever increasing numbers of older people ending their lives in care homes in the UK (Seymour and Clark, 2001; Katz and Peace,2003; SCIE, 2005).

Their deteriorating health and increasing frailty signified to them that they were reaching '*the end of the line*'. Gloria, in particular, lived with progressive and constant decline. The nature of multiple, chronic health problems, experienced over a period of time, resulted in residents living with accumulative loss - loss of functional abilities, capabilities, independence, dignity and loss of possibilities to live life as they wanted to live. Though the closeness of death did not appear to be imminent to the majority of the participants, this remained a possibility and a reality that they discussed:

> *"we are very happy in a way. We all get on very well but there is all these old people sitting. That's why I think that the good Lord, well I believe in Him. I should just go - what is the point? There is none. I am really very Church of England. I am a believer but I just don't see the point... it is sad sometimes as, well I am going off, well you see people. It is sad .....we are all waiting to go."* (Edna: interview 2)

In their daily activities these residents saw the impact of death of fellow residents on others. Residents develop a range of relationships with other people following the move to a care home and some of these relationships can be extremely close and intimate. Thus, when death occurs, grieving for the loss of a friend took place:

> *"there were 2 ladies A....and she made friends with a lady called N. on this side. They were sweet to see together because they used to walk up and down to have their constitutional. A. used to say "Come on N. get yourself pulled together and we will go for a walk" and they used to walk up to the lounge....That was their daily routine. They used to do it once in the morning and once in the afternoon. Then N. died and A. was left on her own..... What a life, what a life. She got so attached to N. that when she died it knocked her right back. She said I will not do that again I will not make any friends like I did with N. I miss her too much. Of course she is left on her own now."* (Anne: interview 2)

Sklar and Hartley (1990) explored the experience of loss of a friend and concluded that surviving friends carry a burden and their grief may not be recognized. The participants in this study were concerned about other people when they observed their deterioration and grieved over their loss. They were critical of attempts to hide death, which was a reality of life in the care home. When the deceased were *'cleverly slipped out'* of the care home, and staff failed to mention that a member of their community had died and this was considered to be disrespectful. They expressed a desire to have a formal recognition of the death of their fellow residents and they felt that bereavement support for fellow residents and family members would be a valuable service in this situation. The ideas that they expressed are not new and have been widely reported in the literature (for example Sidell and Komaromy, 2003; Berndt, 2004).

The earlier discussion in this chapter has highlighted the way that the participants lived with narrative themes from the point of moving into the home. During this phase of their life what they were able to do, what they did and how they were able to do the things that mattered to them changed. As their lives were reaching the end, the following narratives were particularly important to their experience of living in the care home:

- Narrative theme 1: Caring for oneself / being cared for
- Narrative theme 2: Being in control / losing control
- Narrative theme 3: Relating to others / putting up with others.

Attributes of the narrative themes

As discussed in chapter 4, individual narratives are indicative of an individual's experience of life in a care home. In contrast, narrative themes embody the dimensions of residential life that shape a resident's life in a home. Each narrative theme was conceptualized by the researcher as a continuum. The ends of each continuum represented different possibilities concerning a particular narrative theme. For example, the narrative about decision-making, choice and control had 'being in control' and 'losing control' as the end points. Whilst the dimensions of the narrative themes were expressed as polar opposites, the actual experience of residents, as portrayed in their individual stories, could be represented at any point along the continuum depending on context and circumstance.

The end points of each narrative theme continuum were deliberately framed to portray the older person as an active agent in their own life, or as a passive recipient of care. This was important because the narrative themes represented the range of possibilities within each aspect of care home living. At one end of the continuum the older person is portrayed as an active participant in shaping their life in the care home. They were '*caring for oneself', 'being in control', 'relating to others', 'active users and choosers of space', 'engaging in meaningful activity',* and *'living an enriched private life*.' In contrast, at the opposite end of the continuum of each narrative theme, the older person is subject to the forces that operate in the social environment of the care home. A detailed discussion of each narrative theme is provided in the following chapter to portray the type and range of impact that these narratives have on a resident's life in a care home.

Residents' shaping their experience of the narrative themes

Older people are neither inactive, passively receiving the routines of care, or are they independent and self-determining in the way that they manage their daily life. The findings indicate that some older people are subject to the routines of care and have little say in the way that they live their life in a care home. However, others are very active in the way that they attempt to shape their life within the home-wide structures that exist, and they attempt to reconstruct their personal identity, not as a part of institutional processes and structures, but as a person living in that setting.

There are considerable challenges that residents encounter in their attempts to exercise control over their lives, not withstanding the limitations in their ability to execute the choices they make, the attitudes of other people and the organisational barriers that are beyond their sphere of influence (such as the budgetary arrangements for staffing of the home). Amidst the circumstances of daily life, some of the residents in this study were able to exert some control over their situations through a range of strategies. The discussion now examines these.

Extracting resident-led strategies from residents' stories

The participants' stories, discussed in chapter 5, were dominated by descriptions of what happened and when things occurred in the care home. Rarely did the discussion move onto a description of the actions or events that led to those circumstances. Through on-going dialogue between the researcher and the participants, the individual way that they approached and reacted to their circumstances was examined. The outcome of this process led to the identification of their individual strategies. This is illustrated through a description of Charles' actions and the personal strategies that he employed to shape his life in the care home (see table 6.4).

The way that Charles spoke of the strategies that he adopted for living in the care home suggested that he played an active role in determining his life. He made decisions about where he wanted to live and he made decisions about

Charles
– made the decision to move to a care home rather than live with the support of a community care package in his own home
– selected a care home that was located in the community that he had lived in for most of his life and was easy for his family and friends to access
– was determined to adapt to his changing circumstances
– developed a personal routine within the home-wide structures in the home
– maintained regular contact with family and friends by organising a regular schedule for visits and his Tuesday night out with his pals
– sought opportunities to talk with the staff and to get to know them as people - their preferences and interests
– set personal objectives that were achievable in his current situation
– sought ways to be as self-sufficient as possible (e.g. using a slide board to move from his wheelchair to bed without assistance)
– although he could no longer pursue many of his personal interests, such as the physical activities that he had enjoyed he focused his attention on those interests he could pursue through alternative means (e.g. he continued to read, through use of the talking books, biographies)
– modified his room to optimise what he could do in it
– contacted and utilized external agencies, such as the RNIB, for additional support following his move to the care home
– purchased audio and other entertainment systems to enable him to what he wanted in his own room

Table 6.4: Strategies utilized by Charles as a resident

how he led his life in the care home. He was able to carry out some of these decisions without assistance, whereas others, such as contacting external agencies (i.e. RNIB), required the support of family and care staff.

In a similar way the other participants used a range of strategies to influence what happened in their lives. The extent to which they did this varied. Some acted in a similar way to Charles. They identified what they wanted to do within the care home and sought ways to achieve this. Others experienced many physical, cognitive and communicative barriers in identifying the ways that they wanted to live in the care home, and in achieving their desires. Gloria for example, spoke at length about what happened to her. Whilst she did seek ways to negotiate her care with the staff and organise visits from her family, she had great difficultly in communicating her wishes and preferences. Consequently she felt that she had little control over her life.

The key message arising from these findings is the active and individual way that these older people engaged with or attempted to engage with the social

and structural environment of the care home to influence their life as a resident. This is interesting in itself, and challenges the view that older people are passive and powerless in this setting. In the following section the focus shifts from the individual and seeks to describe the patterns and classes of strategies that residents use to shape their lives in care homes.

Resident-led strategies

Through the process of identifying the different patterns of actions and behaviours that were unique to each of the participants, similarities and differences were observed. The following example provides an illustration of one feature of residential life that all of the participants attempted to influence. They all sought to modify their own space in the care home. Though their rooms and the space that they occupied differed, they all introduced personal items to that personal space, thereby changing it into a space that was identified as their place in the care home. Within their personal space many of the participants carefully located their possessions and equipment in positions that gave them ease of access to them, ensuring that they could pursue their interests without relying on the staff for assistance. These actions are similar to the way that individuals modify their homes to enhance the functional, as well as aesthetic, qualities of their environment.

In the care home setting these older people were creative in the way that they developed tools, such as the pulleys Enda developed to open her windows without assistance, to increase the functionality of their environment. In addition, they also found that they had to develop ways to overcome the intervention of others when this potentially undermined their efforts. For example, a well intentioned cleaner tidied away the ropes that Edna had meticulously placed near her chair to enable her to open her patio door. The room may have been tidy but it no longer served the purpose that Edna intended. When Edna replaced the pulleys she insisted that notes requesting the cleaners to leave her equipment in place, which she made, were left around the room. This situation points to important features of resident-led strategies. First, it highlights the way that residents actively seek to change

their lives in the care home - Edna made well-planned efforts to enhance her independence through the use of the pulley system; secondly, it points to the possibility that staff are not always aware of the actions of residents - the cleaner lacked knowledge of the way that Edna used the ropes to open her doors without assistance; and thirdly it illustrates how the efforts of residents can so easily be undermined by care staff if they are unaware of what residents attempt to do.

Collectively, the descriptions of different types of resident-led strategies that were collated had the potential to lead to infinite description of what the participants did in their everyday life. This process, however, does not develop an understanding of the range or types of strategies residents adopt in their lives. For the purposes of conveying ideas about types of resident-led strategies adopted by the participants, the strategies were mapped onto the narrative themes discussed in the earlier part of this chapter. The results,

Resident-led strategies:

Narrative theme 1: Caring for oneself
- negotiating care and/or assistance with staff, family and friends to identify opportunities to self-care and maximize independence
- modifying the environment to serve their own purpose
- proximal location of equipment/tools to optimize access and ease of use

Narrative theme 2: Being in control
- taking part in decision-making concerning care and life-style
- taking part in decision-making concerning the community in the care home
- seeking ways to implement decisions with and without support
- using communal and personal (relational and financial) resources to implement decisions

Narrative theme 3: Relating to others
- seeking opportunities to interact with others that they select to be with in the home
- taking part in communal routines and activities
- becoming familiar with staff and identifying mutual interests as a basis for a relationship founded on reciprocity in addition to the functional cared-for / carer interactions
- negotiating a regular program of visiting with family and friends
- using different approaches to sustain contact with family and friends

Narrative theme 4: Active users and choosers of space
- personalizing space through the introduction of personal possessions
- modifying space to optimize its functionality
- changing space to create a social environment to entertain guests

Collective story 5: Being supported to engage in meaningful activity
- seeking ways to maintain life-long interests
- adjusting goals to circumstances
- negotiating access to services (e.g. RNIB)
- securing resources to enable them to pursue their own goals

Narrative theme 6: Having an enriched private life
- adjusting goals to circumstances
- working within existing home-wide structures
- identifying what can be changed in existing home-wide structures to accommodate preferred life style and how this can be achieved
- negotiating alternative ways of living in the care home
- securing support from staff, family and friends to create a life in the care home

Table 6.5: Resident-led strategies

presented in table 6.5, are qualitatively different from the descriptions of the strategies used by Charles (see table 6.4) to reflect the shift from the actions of an individual to a more general description of a class of resident-led strategies. The findings presented here draw on the stories of residential life from a limited data set, so there is no suggestion that the table includes a comprehensive list of all the possible strategies that exist.

A typology of resident-led strategies

Following further examination of the strategies that residents use in their daily lives, patterns relating to the way that these were initiated and implemented were observed. The strategies were therefore categorised as follows:

- *Resident initiated / resident implemented strategies* - in this situation the individual identified what needed to take place to influence their life in the home and they acted to achieve their objectives
- *Resident initiated / other executed strategies* - in this situation the individual identified what needed to take place to influence their life in the home and they enlisted the support of staff, family and friends to assist them to achieve their objectives
- *Resident negotiation to identify possibilities for living in the home and ways to achieve these* - residents participated in decision making processes such as care planning and resident committees with care home staff to influence their daily life in the home.

These types of strategies are different in nature and quality. Describing residents' decisions and actions in this way progresses an understanding of the different strategies they adopt in their lives in the care home. For purposes of description, this is identified as a typology of resident-led strategies. Within one class of resident-led strategies, the locus of control rests with the older person who makes judgements about what needs to happen and decides how to achieve this. Here the older person requires personal ability(ies) and

resources to carry out their decisions. The example of Edna's pulley system to open her windows and patio doors is a good illustration of this.

In many situations, however, residents can decide a plan of action but need support and assistance to carry out such plans. In this second class of strategy, the older person maintains a high level of participation in the decision-making process, yet their influence is reduced as they are reliant on others to execute their plans. In the situation where Charles' decided to go out with his friends every Tuesday night, he was reliant on their availability and willingness to meet him in the agreed place, and on the support of staff to assist him to access the building.

In the third class of strategy within the typology the locus of control moves from the resident and is shared between the older person and others who decide what is to happen and how it is to be achieved. For example, Anne negotiated with the care home staff and telephone company for a private phone line in her room to enable her to contact her family and friends. Though she gained agreement the care home company and the telephone company, and obtained a phone and access to an independent line, when problems with the line occurred she experienced great difficulty in overcoming complex negotiations to have the fault repaired.

The development of the typology of resident-led strategies provides a framework to think about the different ways that older people do influence the structures of their daily life. It also highlights the importance of developing ways to identify those things that residents do that are important to them, in an attempt to support and facilitate their efforts.

Conclusion

As the findings in this chapter show, the interpretative process brought the narrative themes that all residents experience following their move to a care home to light. This is unsurprising because shared stories and shared

narratives are a common feature of situations where communities of people experience similar, or the same, social conditions. What is unique to this study is the identification of the 6 narrative themes that concern care, control, relationships, place, activity and the multiple-layers of living.

The evidence indicates that residents use many different strategies to influence each of the narrative themes that permeate their life in a care home. The strategies that residents adopt promote their independence and enable them to do the things that they find meaningful. In situations where they are unable to implement their choices, older people seek assistance from family, friends and care staff. The support that they receive, however, varies. In some instances resident's choices are acted upon, and in others they are ignored. In many situations, however, the findings from this study indicate that other people are often unaware of the older persons' decisions and that they had no knowledge of their actions. In this case the older person was not supported in their endeavours to direct their own life.

This interpretation of the way that older people live in care homes challenges the view that older people are inactive, passive inhabitants of the residents' world in the home. Indeed, this interpretation portrays residents as active inhabitants of a world where they strive to reconstruct their life in an environment that poses many challenges, not least living a communal environment where others live and work. The ideas that are introduced in this chapter are developed in the following chapter by examining each narrative theme in detail to describe and illuminate the influence that they have on residents' lives.

Chapter 7

Living with the narrative themes – Critical in-depth interpretation

Introduction

Through the process of the cross case-reconstruction analysis, as discussed in chapter 6, the narrative themes that impact on residents' lives were identified. An individual's experience of each of these narrative themes is constructed as they work to shape their life in the care home. Consequently, there is a dynamic interplay between the experience of each resident and the narrative themes. It is also important to highlight at this point that the narrative themes are presented as separate aspects of care home living for the

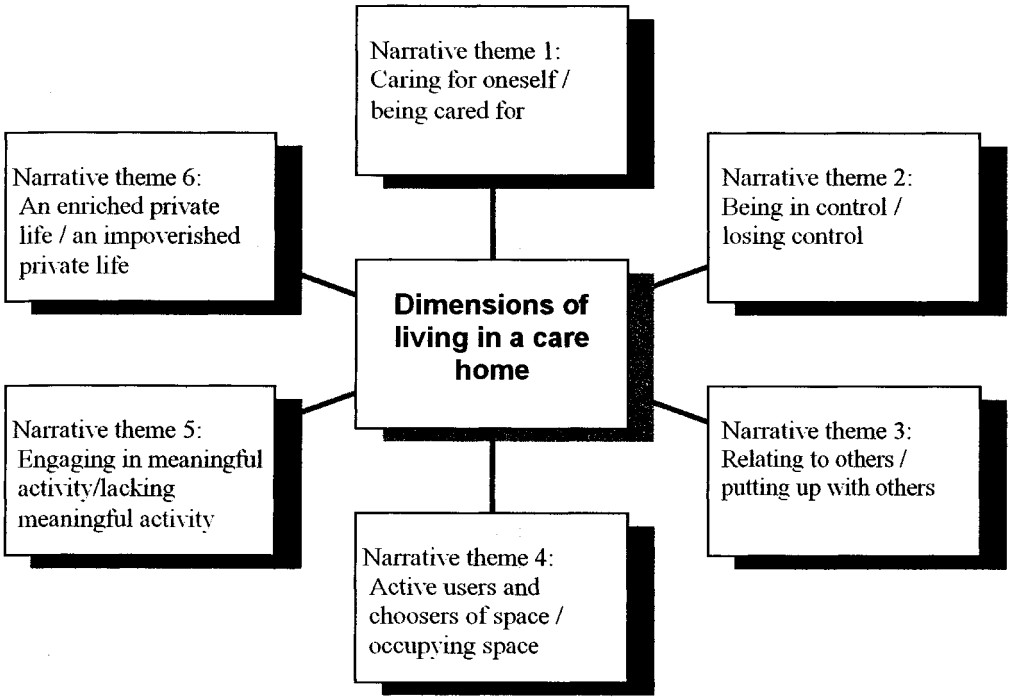


Figure 7.1: Dimensions of care home life as perceived by older people

purposes of description, yet the narratives themselves are interconnected dimensions of the social environment where the older person lives. As such there is a close relationship between individual experience and community dynamics, and between each of the narrative themes, depicted in figure 7.1.

Whilst acknowledging the interrelatedness of the narrative themes, each narrative is examined separately in this chapter to develop an understanding of life in a care home. Understanding during the critical in-depth interpretation was derived through a process of interpreting the narrative themes throughout the fourth stage of reading texts. These texts were available through multiple sources such as the stories told during the narrative interviews, discussions between the researcher, residents, family, friends and staff during visits to care homes, and professional and academic literature relating to care home life. Engaging with these different text sources led to a sense being made of the narrative themes and the diverse stories that the participants told of their experiences relating to these narratives.

Narrative theme 1: Caring for oneself / being cared for

The transition from independent living to requiring care

Many different factors pre-empt an older person moving to a care home. Acute and chronic illness, disability and increased frailty were key factors that contributed to situations where the participants were unable to meet one or more of their self-care tasks. Thus, they needed assistance with dressing, using the toilet, bathing, feeding and mobilising, as well as nursing care to address health-care needs. Being unable to care for oneself within the essential aspects of living is not uncommon for frail older people. A recent report by the Office of Fair Trading (2005) indicated that the majority of care home residents (75%) are classified as severely disabled at the point of moving to a care home, and this is often followed by subsequent decline.

Moving to a care home is a major life transition for older people as they *'let go'* of their previous life-style and move to a place where they are dependent on

staff for support and assistance. This is a new experience for some people. In this study, Beatrice, Charles, Doris, Edna and Florence, indicated that they had '*managed fine by themselves up until now'.* Sudden illness had resulted in disability, hence they needed long-term care. These precipitating factors have been widely reported in the literature as discussed in chapter 2 (p.31).

In contrast, Anne, Gloria and Harriet had experienced declining health for some time and the move to the care home took place when they could no longer live without a greater level of care in their own homes. Knowing that her health would continue to decline Anne selected relocation to a care home from the many options that were made available to her. Although Gloria and Harriet acknowledged that their health would continue to decline, they did not anticipate that they would require different care arrangements in their later years. The sudden death of Gloria's husband and Harriet's sister's concern over her ability to continue to care brought their situations to a crisis. The literature that focuses on the move to a care home (e.g. Rosswurm, 1983; Allen et al, 1992 and Burholt 1998) has highlighted the impact of these types of social and psychological crises precipitating the move to a care home. Whilst Gloria and Harriet had experienced living with dependency for many years, they suggested that being dependent on others in the care home environment was different. They were now cared for by staff who lacked detailed knowledge of their preferences and dislikes and they had to cope with unfamiliar, and in some situations, unwanted care practices.

Dependency in daily life

When care staff provided assistance to residents with their self-care activities, the participants felt that this help resulted in intrusive care procedures. In addition to staff assisting them with what had been private activities, the participants were aware that other residents knew what was happening to them throughout the day. Gloria, for instance (p.159), spoke of her dislike of a fellow resident counting how many times that she went to the toilet during the day. '*Turn-taking'* was a feature of group care that involved waiting for assistance, and this ensured that staff, residents and visitors knew about their

most private bodily functions. The public nature of being cared-for is stressed by Beatrice:

> *"The toilet is bad here, because everyone has to be taken to the toilet you know. When you are waiting to go oh dear it is awful."*
> Researcher: *"Is that waiting while other people go to the toilet?"*
> *"Well yes most people go in chairs you see, and you have to wait until someone can take you. It is not very nice having someone standing over you while you are having something. You are never, never on your own. Never, never."*
>
> (Beatrice: interview 1)

Bodily functions were also made available to public scrutiny through care practices within the homes. The regular routine of *'the weighing'* that Florence discussed (p.151), is illustrative of these practices. This practice points to the way that dependent residents are subject to a range of institutional practices that make what had previously been private matters, public.

People's experience of dependency is inextricably linked to the quality of care that they receive. Though quality of care means different things to different people (Raynes, 1998; NCHR&D Forum, 2006) in the main quality care takes into account and addresses people's physical, social and emotional needs (E-Map, 2001). There is evidence, however, that care home staff prioritise residents' need for physical care over their need for social and emotional support (Nolan et al, 1995). Certainly, some of the case reconstructions in chapter 5 highlighted the residents perception that staff were busy with routines of care that were focused largely on meeting physical needs, whereas they felt that their social and emotional needs were given little attention.

Doing as much as possible for oneself

Though the participants acknowledged that they needed considerable assistance and support in their daily lives, they made continuous reference to the importance that they attached to doing as much as possible for themselves. In contrast to the public spectacle of care that took place throughout the day, the participants devised ways to continue to self-care.

Often this was in the privacy of their room, and unbeknown to others in the home. Throughout the narrative interviews there were numerous examples where the participants had designed gadgets and tools to do things without assistance. Charles, in particular, pointed out the importance of being as independent as possible and he felt that being able to do things for himself enhanced the quality of his life:

> *"Oh I can control my own life.....and that is a big thing. You know I wouldn't like to keep having to ask the staff to take me here or to do this for me or do that. When you can do it yourself it is much better. It makes it, it makes your life more pleasant."* (Charles: interview 2)

The participants spoke of their fear that their abilities would decline and this would result in a situation where they would be less able to do things for themselves. This motivated individuals to develop strategies to maintain and enhance their existing abilities. Edna, for example, developed an exercise routine that she followed every day prior to the staff assisting her out of bed in the morning. The routine consisted of hand, elbow and shoulder exercises. She genuinely feared that further loss of movement in her arms and hands would limit her ability to feed herself. If this happened she would be moved to the table in the dining room that was set aside for those residents who required assistance to feed themselves (see p. 145 & 153 for discussion of Edna's and Florence's views of this practice and the effect on their lives).

The participants developed different strategies to enable them to do as much as possible for themselves. They wanted to be as independent as they could within a supported living environment.

Environment-induced and other-constructed dependency

The residents were quite frustrated and annoyed when the environment and practices in the home undermined their efforts to self-care. They were rarely consulted about the furnishing, decor or design of the building that they lived in. Willcocks et al (1987) pointed out that this was common practice approximately twenty years ago and, at that time, they highlighted the insights that could be gained from examining these issues with residents in an attempt

to develop enabling environments that supported people to undertake everyday activities with minimal assistance. In the following story, Anne spoke about the refurbishment of her care home and the impact that the new deep-piled carpet had had on her routines:

> *"Well I have lost a little bit of independence again, haven't I? I am used to losing a little bit every now and again. Now I have to ask somebody to push me back* (from the front door to her room). *Well before on the other carpet I could just wheel down and wheel back with about 5 minutes rest at the other end. I used to like to go down and collect any post like tapes and things that were down there for me in the mornings. And sometimes they are too busy to bring them up and I used to enjoy that because it was something that I could do for myself. But I can only manage one way. Never mind I will get used to it I suppose."*
>
> (Anne: interview 6)

She had voiced her concerns about the new carpet to the staff and in response they offered to push her chair to the front door whenever she needed assistance. Their reply indicated to her that they failed to recognise the loss of independence that she experienced and the value that she attached to doing things independently. Moreover, the place that she now lived in contributed to a handicap that she hadn't experienced previously. In a discussion of accessibility, Peace and Reynolds (2004) stressed the importance of designing care homes to compensate for disability and maximize residents' independence. Features such as placing mirrors at wheelchair height, can enable residents to groom themselves (Kane, 2001), and access to assistive devices made available through NHS loan equipment services (DoH, 2004 a, b; Swann, 2005) can enhance the functional ability of residents. None of the participants, however, had been offered access to this type of equipment and their accounts provided evidence that the environment itself limited what they could do without assistance.

In summary, the stories told by the participants shed light on their views about '*caring for oneself and being cared for'.* Whilst most spoke of the staff as well intentioned and doing their job effectively, they disliked the dependence that they had on them. Consequently, they strived to be as independent as possible and did as much as they could for themselves. Practices in the home

and the environment itself often undermined their efforts, suggesting that the staff did not support those efforts, or were unaware of them.

The portrayal of residents actively attempting to be as independent as possible within their restrictions provides an alternative image to that of the older person passively receiving care and *'fitting in through meshing oneself with the circumstances of residential home life,'* which has been widely portrayed in the research literature according to Lee (2002), following her review of 30 years' research into older people's experiences of residential care placement. Older people want to be enabled to self-care within the supported living environment of a care home.

Narrative theme 2: Being in control / losing control

Residents' involvement in decision-making

Throughout the narrative interviews there were many descriptions of situations and events where participants made decisions and acted on them. Charles (see p.133), for instance, spoke in detail of the way that he had planned and organised his days. He structured his routines to ensure that he could get up at a time that suited him in the morning, allowing adequate time to attend to his personal hygiene with minimal assistance. He organised his morning schedule to meet with other residents and the staff. This provided opportunities to find out what was happening in the home so he could make an informed choice about the way that he organised his day. Whilst he was able to determine many aspects of his life, the way that he worked around the set routines of the home indicated that he perceived that there were limits to what he could and could not influence.

This does not suggest that the residents did not voice their opinions about the day-to-day management of the home. There were many stories that referred to situations where the participants had made their views known to the staff. For example, Anne had experienced the impact that the new carpet would have on her life (discussed on p.198) when in was fitted in the room used as a

hair-dressing salon, a week prior to the fitting of the same carpet in the remainder of the home. Thus, she recognised that she would be unable to move her wheelchair without assistance. Although she held the view that the staff were experts who would have taken into consideration the impact that increased friction of a deep-piled carpet would have on movement of wheelchairs in their decisions about refurbishing the home, she shared her experiential knowledge of this carpet with the staff. At the point when she talked with the home manager about the carpets they had been on order for some time, so she had no influence in this situation.

In other circumstances, such as the residents' committee, she took an active role in decisions about communal activities, the menu and practices in the home. The agenda for these meetings, however, was only partially controlled by residents. Taken together, these situations reinforced her perception that there were aspects of living in the care home where she could exert limited control.

These examples are representative of the different types of involvement that the participants had in decisions that affected their lives. In some cases they were central to decision-making processes and in others they were marginalised from these processes and were merely informed about what would take place in the home.

Types of decision-making

In addition to highlighting the range of involvement in decision-making, the above illustrations also serve the purpose of differentiating the types of decisions residents make. These include micro-decisions (decisions about care, treatment and individual life-style), and macro-decisions (decisions about the operation and management of the home). Across the care homes that participated in this study there were organisational structures (i.e. residents committees; quality improvement activities) and care management practices (i.e. key worker systems) that encouraged and supported residents to participate in a range of different types of decisions.

Without exception, the participants focused on those aspects of life in the home that they could still control and, in the main, these involved micro-level decisions. Kahn (1990, 1999) reported similar findings and argued that residents' efforts were directed to those areas of life that they believed were within their sphere of influence, such as the time that they went to bed, whether to participate in the communal activities of the home, and engaging in self-care. Khan also found that residents directed their efforts to transforming the negative aspects of the nursing home. He argued that their efforts to control these activities were a coping strategy that they adopted to "*make the best of it*". Moreover Kahn emphasized the point that residents did not want to give primacy to things that they could not change. Anne's passive acceptance of her increased level of dependency on the staff following the refurbishment of her care home was, perhaps, indicative of her acknowledgement that she could not change what had happened.

Being able to make decisions and act on those choices

The extent to which the participants were able to make and act on their choices was very idiosyncratic. Though Anne was unable to influence decisions about the refurbishment of the care home she was instrumental in determining other aspects of her life. For example, her long-term friend visited her three times per week following the move to the care home. As the years passed by her friend's mobility deteriorated as a consequence of Parkinson's disease. It was Anne who broached the subject of changing visiting arrangements. At first her friend resisted the notion of meeting less often, but did eventually agree to their '*night-in*:'

> *"I said, 'Now look, you are doing far too much.' (*She was trying to help her grand-daughter with the new baby and continue visiting.*) It wasn't doing her any good so we cut it down to 1 night per week. So she comes on a Thursday night. But she is always there 6.30pm on the dot."*
>
> (Anne: interview 3)

Her limited functional abilities prevented her from carrying out many of the decisions that she made, so she entered into complex negotiations with staff and her friends to support her to act on her choices. With their eager

assistance, she shaped her life as a resident. In contrast, Beatrice, who lived in the same home, felt that she had little control over her life. Her routines were determined by the care staff and she had little say in what happened to her, how she was dressed and with whom she interacted (see p.126 for detailed accounts of her daily negotiations with staff). She frequently challenged the decisions that the staff made and in situations where those decisions were offensive to her she persisted to highlight her view as illustrated in the story that she told about wanting to wear a vest (p.127). It was only then that she was supported to act on her choices.

Both of these women were unable to carry out the decisions that they had made, so it could be argued that they experienced a loss in personal autonomy. Yet the evidence clearly indicated that they were able to make decisions and their problem rested with their inability to act on their choices. This reflects the distinction that Collopy (1988) made between decisional and executional autonomy (see p.38, bibliographic overview), and points to the problem of a simplistic understanding of autonomy as the right to make independent decisions.

In their interaction with staff the participants experienced different encounters. In some situations there was acknowledgement of the abilities that remained and enabled them to participate in some aspects of decision-making. When the staff supported them and compensated for abilities that they lacked they were enabled to take and make decisions. In other situations, the staff controlled the decision making process resulting in individuals being restricted to limited expressions of who they are and what they wished to accomplish. Decision-making, therefore, in the context of a care home is not entirely straightforward. It is the outcome of a complex interaction between person, context and process, where older people can take part in decision-making if they are given the appropriate type of support (Flower,1993; McCormack, 1998; Raynes, 1998; Reed, Cook, and Stanley, 1999).

Although discussion with staff was an inherent part of the participant's daily negotiations in the care home, more continuous discussion occurred between

residents to shape their existence in the home. In the following extract Beatrice described a situation involving the use of her wheelchair as a communal resource. She was aware that some of the residents who used her chair were incontinent and it was not washed between uses by different residents. Her concerns had increased, so she decided to discuss the ownership of the chair with another resident who became verbally aggressive. The discussion then focused on finding a way to resolve the situation without shouting:

> *"J. was sitting around the corner in a chair. A red chair. My chair is black. I told her that she's got my chair and she said, "Nobody has got anybody's chair." She said, "That is my chair." Well I said, "Ask and we won't have any shouting like that." I said, "Go to the office and ask if you have got the right chair." And she said, "Oh you. You are always like that." I said, "That is the only way to settle things not shouting and having the whole place disturbed. Because the old ones get upset."*
>
> (Beatrice: interview 4)

Daily life involved negotiating changes in the actions or behaviours of other residents. These stories embodied the tensions that they encountered through living with others. One response to this was entering into negotiations whereby they attempted to strike a balance of shaping their personal niche of the public world of the home whilst not upsetting others and possibly being marginalised from the resident group.

In summary '*being in control*', or '*losing control*', was a complex dimension of life in a care home. There were many factors that influenced whether an individual had more or less control in their life and this was not restricted to whether they were able to make choices but to act on them.

Narrative theme 3: Relating to others / putting up with others

Changes in social relationships

With the move to a care home the participants experienced changes to their relationships with other people. Immediately following relocation their contact

with family, friends and neighbours was reduced to visits. During these times familiar patterns of interaction no longer existed, which had the potential to put a strain on their relationship. They also faced the transition to living in a communal environment where they had continuous contact with people who lived or worked in the home. This opened up the possibility to them of developing new relationships, as previously reported by Reed and Roskell Payton (1996) and Hubbard, Tester and Downs (2004). Their interaction with family and friends, fellow residents and staff was qualitatively different so these are discussed separately below.

Interaction with visitors (family and friends)

The period of moving-in involves a process of separation and adjustment for the new resident. The participants endeavoured to keep in touch with family and friends and were sad when they were unable to do this. Being able to continue to interact with these people was valued as this enabled them to maintain links with their personal history, keep up-to-date with events in their family life, continue to share intimacy with people that they trusted, and enjoy companionship.

The value of maintaining interaction between residents and their family has been widely reported, with accounts of family involvement facilitating individualized care, providing links to the older person's history and their preferences, and enhancing the quality of life of the resident (Ekman and Norberg, 1988; Rowles and High, 1996; Friedmann et al, 1999; Sandberg, Lundh, and Nolan, 2001). Similar attention has not been given to understanding the benefits of sustaining long-term friendships following the move to a home.

Relationships with family and friends are different. Rather than developing from familial ties, friendships emerge from intimacy, mutual understanding and reciprocity with another person (Jerrome, 1993). In a review of the literature, Slater (1995) concluded that the value of friends in later life rested in opportunities to give and receive aid, affection and affirmation to one another. The participants particularly valued interacting with their friends.

Anne experienced considerable pleasure during her *'nights-in'* with her friend (p.121), and Charles looked forward to the conversations that he was able to engage in with his friends (p.134). These friendships resulted in pleasure, fun and enjoyment, thereby satisfying their emotional need (Cook, 2006, back cover off print).

The participants made reference to the advanced age of their family and friends and to their changing circumstances. They were aware that illness and disability had the potential to lead to a breakdown in their relationship with these people if they were unable to contact one another. In response, they implemented a range of strategies to sustain these relationships through developing alternative ways to keep in touch, such as telephone conversations on private lines, use of mobile phones and letter writing. In the future the use of e-communication will enhance contact between those living in a care home and those at home.

Interaction between residents and staff

The participants engaged in different types of interaction with staff. These interactions could be broadly categorised as functional and relational types of social exchange. Functional interaction accounted for the majority of the exchanges between residents and staff, with this being centred on requests from residents for assistance, staff seeking information to clarify what the residents needed, and staff providing information to residents about routines and events in the home. The sharing of these different forms of information served the purpose of identifying and responding to resident's needs, and to facilitate the smooth running of the care home.

In contrast relational types of interaction between residents and staff were focused around the sharing of personal information or subjects that were of mutual interest. The participants valued the opportunity to enter into social exchange in this way as it enabled residents and staff to get to know each other, providing the foundation for the development of closer relationships. Importantly, this form of social interaction provided opportunities for residents to experience companionship and reciprocity in their daily lives, which is

essential to well-being (Roe et al, 2001, Davies, 2001a). Factors such as high staff turnover and intense staff workload mitigated against residents entering into relational forms of interaction with staff (p.123).

Contact, acquaintanceship and friendship between residents

From the privacy of their rooms, residents were aware of the comings and goings of other residents. The lack of sound proofing in the care homes ensured that they could hear their neighbours' televisions and the conversations that they had with staff and visitors. This background noise reinforced their knowledge of others being around them. This was '*comforting*' to those who had lived alone and had feared that they would be by themselves when they most needed help. These background encounters were important as part of the general milieu of the home and listening to or '*eavesdropping*' contributed a different dimension to their life. Living with disturbances was part of the way of life and tolerated most of the time. For instance Charles spoke of the noise from his neighbour's room when the staff assisted her out of bed in the morning. The sound woke him up everyday, so he used this as a signal to have an extra 30/40 minutes lie-in prior to preparing for breakfast. When disturbances could no longer be tolerated or were unexpected, such as someone walking into a bedroom without being invited, the contact with others in the home was perceived as uncomfortable and, at its worst, frightening.

The structure of the day inevitably led to contact between the residents. This was often welcome as it provided an opportunity for what Gutheil (1991) described as the most popular resident activity - talking. The most common conversations centred on what was taking place in the care home and events that they had heard reported on the local and national news. This form of contact was important to residents:

> *"What I was meaning is I like to talk to everyone in my corridor but they are not necessarily my friends, they are neighbours. But I value them and think highly of them. My relationship is more of an acquaintanceship."* (Anne: interview 5)

These encounters were important opportunities to get to know others living in the home. Rarely, however, did the interaction develop further. Personal attributes and abilities, such as hearing, vision, speech, mobility and cognitive ability, restricted their interaction and limited the possibility of fostering friendships and identifying common interests. Though these issues have been discussed in the research literature (see Retsinas and Garrity, 1985; Mor et al, 1995; and Kovach and Robinson, 1996), the stories told by Anne (p.122) of the way that her lack of sight impeded her recognition of fellow residents, thus creating the perception of her as being *'rude',* and Charles' anguish over not being able to meet someone who could engage in a hearty discussion, highlight the difficulties that residents experience. As individuals living in a setting where others are infirm and disabled they are unable to compensate for each other's limited abilities. The staff appear to be unaware of their difficulties. Therefore they do not provide the necessary support to foster potential relationships. Consequently, residents such as Anne retreat to the sanctuary of their room as a way of avoiding potentially embarrassing situations (see Cook et al, 2006 back cover off print for further discussion).

Those who were immobile were limited in the type and frequency of contact they had with different people. They relied on the staff to take them to the public areas of the home, and the seating arrangements in these areas dictated the people with which they interacted. In some situations this led to informal discussion and identification of common areas of interest. In other situations, being positioned in close proximity to some residents was unpleasant. Beatrice's story (p.128) of sitting next to a woman who drank from her cup and took food from her plate at mealtimes is a good illustration of this. Meal times are an important social event during the day, but for this woman they were a constant source of aggravation leading to conflict with other residents and angry outbursts.

The majority of interaction between residents could be best described as living alongside others. Such relationships did not lack emotional investment. There was concern for the well-being of others – as exemplified in the way

that they asked after each other when not observed fulfilling their regular routines, or when they acted as advocates for each other as the need arose. Interacting with fellow residents and getting to know others was portrayed as a complex process. Building up relationships with other residents was assisted by having something in common, such as living in the same locality, or having mutual interests. Where there was no link with the past, the process was even more difficult. As residents in a care home, individuals were often thrown together out of their need for care rather than creating the possibility of entering into meaningful social interaction leading to the development of new friendships in later-life. In this case *'putting up with others'* best described the social interaction that older people experienced in the care home.

Narrative theme 4: Active choosers and users of space / occupying space

Having your own place within the care home

Though some of the participants were involved in decisions about the care home that they moved to, very few had any choice about the room that they moved into. In the main, the rooms were allocated to them and they expressed views that were represented by this comment - '(I'm) *very fortunate to move to the home of my choice and have a room of my own'.* Single occupancy rooms have only recently become the accepted norm. A study by Netten et al (2001) indicated that a proportion of beds (11%) in Local Authority and voluntary sector residential homes were occupied by more than one person, with this proportion increasing in dual registered (31%) and nursing homes (35%) (see also Counsel and Care, 1991; C.P.A., 1984; 1996). Pressure to cease the use of shared rooms in care homes culminated in this being endorsed in the UK through regulatory processes with the introduction of the National Minimum Standards for Care Homes (DoH, 2001).

There was evidence in this study that residents could indicate their preference to occupy a particular room, and when the room became vacant staff assisted them to move. Being able to do this was very important as it was one of the

ways that they were able to influence what they referred to as their *'space'* in the home. This was a limited space where rooms could be as small as 10 square meters (Kellaher, 2000; Hanson et al, 2003). Whilst it may have been limited, the position of the room was important if it enabled them to observe and interact with the environment outside of it in a similar way to that described by Rowles (1981) and Parker et al (2004), as discussed in chapter 2 (p.23). The participants utilized the zone that was outside of their immediate physical environment by carefully positioning their chairs to optimise their view of the external world.

Some of the residents actively extended their territory within the home. For example, Florence made considerable use of the area outside of her room. Throughout her life she had been a keen gardener and following the move to the home she transformed the small terrace area into her private garden. She also had a bird table placed in the centre of the terrace, which enabled her to watch the birds feed. Being able to do this gave her much pleasure and added an additional dimension to her life. In this quotation she talks about the support she received to cultivate the wildlife that she watched:

> *"Can you see the birds?"*
> Researcher: *"Oh yes, do the plants attract the birds?"*
> *"And the seed."*
> Researcher: *"Oh I had not noticed that."*
> *"My carer, Mrs T. brings the seed and nuts. When the pigeons come they all go away."*
> Researcher: *"There are half a dozen up there now."*
> *"There are certain times for feeding - about 3.30pm."*
>
> (Florence, interview 2)

In contrast to Florence, who spent a large proportion of her day in her room, other participants - Beatrice, Doris, Gloria and Harriet - tended to spend much of their days in the public areas of the home. The earlier discussion about Beatrice's (p.168) minimal input into designing her room drew attention to her occupancy of this room rather than her control of this territory. Throughout the discussions these residents made frequent reference to their *'place'* in the lounge or dining area and their *'chair'*, and so on. Declaring ownership of a territory in public spaces is not uncommon in institutional environments

(Sommer, 1970). Within these public areas of the home the participants attempted to modify that place from being a space that they occupied, to a place that had some meaning for them. They placed their personal possessions on the table and on the window sill near to their chair. This served several purposes. The objects marked the borders of their space but the placing of these objects also transformed this space into an aesthetically pleasing and a functional space. Reed and Payton (1996) also pointed out the way that selection and occupancy of seating in these areas of the home influenced the interpersonal interaction that took place.

Intrusions into personal space

Staking out the borders of personal space was very important in the care home environment. Essentially, care homes are very public environments where residents experience little privacy (Counsel and Care, 1991). None of the residents had locks on their rooms, so the only barrier between them and the world of the care home was their doorway. During the interviews it became evident that staff often entered residents' rooms without knocking on the door and waiting to be invited in. This tended to be accepted by the participants as an inherent part of living in the home.

The same reaction was not afforded to the uninvited intrusion of other residents. During her second interview Anne gave an account of a situation where two residents, who were temporary boarders in her home, wandered into her room at all times of the day. She disliked this, and at times was frightened by their behaviour:

> *"Oh I didn't like that at all, I thought that was very rude of them. It was nasty people just wandering in and out of your house without being invited.....this is the only space that I have got and I am going to keep it. I don't see why I shouldn't either."* (Anne, interview 8)

Using space

Within their private rooms the participants had personal items on display. These items had been carefully selected and they were invested with

personal meaning. The paintings on Florence's walls, for instance, were the only links that she had with relatives who had died. The chair in Beatrice's room was the only piece of furniture that she had been able to keep with her through her relocation from the home she loved to sheltered housing and, now, the nursing home. They had been encouraged by the staff to bring their cherished possessions with them and in the context of the home these items took on a particular significance. At once they both represented a life that had past and embodied the memories that were associated with that time. Hoskins (1998) described residents' personal possessions as *'biographical objects'* in order to highlight that these items - furniture, ornaments, pictures - were significant in that they represented something rather than simply being what they were. The notion of objects being biographical suggests that they embody clues to an individual's personal identity, as illustrated in the following quotation from Hoskins:

> 'entangled in the events of a person's life and used as vehicle for a sense of selfhood' (p. 2).

Moreover, by introducing their own objects and furnishings into their room the participants actively transformed the neutral space that they occupied into behaviourally significant and meaningful space. They were highly active in this process and where they were unable to modify the environment themselves they sought assistance from others to do this. As they changed their environment it acquired metaphysical, experiential and social dimensions in much the same way that an individual's home has been portrayed in the literature (Gurney and Means, 1993; Golant, 1998; and Heywood, Oldman and Means, 2002). The space also acquired a functional dimension when it was modified to enable the individual to engage in activities that were meaningful to them. These findings reflect the ideas of Lawton (1968), Leon, Pastalan and Carson (1970) and McAuley and Usita (1998), amongst others, who argue that older people alter their environment or vary their behaviour to adapt to a relatively fixed environment to meet their needs (as reported in Cook, 2003).

In a series of studies drawn together by Leon, Pastalan and Carson (1970), the importance of older people shaping their micro-territory within congregate living settings was highlighted. For those living in long term care settings, their territory is reduced, with some residents being restricted to the confines of their room. Within this collection of works, the authors argue that in these circumstances older people spend more time in the same setting and, consequently, the proximal environment assumes greater importance than it would to others who are more mobile. From the stories the residents told, it appears that their proximal environment depended largely on the place that they tended to occupy within the home.

The participants' accounts portrayed care home residents as '*active choosers*' and '*users of the space*' that they live in, in the care home. The extent to which they were able to do this did vary according to the individual's abilities and the help that they were able to enlist to support their efforts. As a result of their efforts they changed their place in the home in ways that reflected their uniqueness and they transformed their environment into a place that had meaning for them (Cook, 2003).

Narrative theme 5: Engaging in meaningful activity/lacking meaningful activity

Having something to do

What the participants did and how they did those things was the focus of many of the stories that were retold. Their days were shaped by the routines of the home and attending to personal care. By far, talking and interacting with fellow residents and the staff in the home was the most evident resident activity. This was rarely described as dialogue that was invested with personal meaning. Discussion with other residents was described as a way to '*pass the time*' during what they perceived to be long, empty days; and the main function of communication with staff was to ensure the smooth execution of tasks. When communication with others moved beyond fulfilling a specific function, they entered into a time in which they engaged with other people.

Eyers' (2003) study, comparing life and work in English and German care homes, highlighted the importance of communication as an instrument of care. Whilst she argued that the purpose of information passed between residents and staff was to support the completion of bodywork, this also enabled emotional exchange between these people.

The participants in this study desired interaction with other people that was more than a functional exchange of information. They wanted to get to know others in their home and to be able to share their lives with them. Communal activities were an important vehicle that enabled residents and staff to communicate with each other about something other than care. Edna, Florence and Doris' discussions of the varied, lively activities programme in their care homes illustrated the importance of *'having something to do'* which facilitated interaction within the home. They were enabled to do this through the support of staff and practices within the home that facilitated communal activities. The employment of a dedicated activities co-ordinator or diversional therapist in care home C, in particular, led to the development of an activities programmes that the residents could select to take part in.

These discussions sit in great contrast to those of Anne, Beatrice, Gloria and Harriet, who spoke of the *'sameness of it all'* - the relentless routines that dominated their days and the boredom that resulted from doing nothing but sleeping and waiting. With the support of staff and friends, Anne had developed a range of activities that she could do within the privacy of her room. Nevertheless, she found that life in the care home was largely monotonous. The other 3 participants spoke of their desire to take part in purposeful activity but they had access to little or no resources to do this. These findings suggest that there were three dimensions to activities that were important to residents. These were the extent to which they take part in activities, what they did and the resources that they drew on to enable them to take part in meaningful activity.

How much activity do residents take part in?

Though there was no attempt to measure resident activity in this study, it became apparent through the individual stories that each resident's level of activity differed. Research from the 1960's onwards has consistently highlighted that the majority of residents' days are spent doing little or nothing. Nolan, Grant and Nolan's (1995) study of resident activity in a Welsh nursing home identified that approximately 70% of the time residents were engaged in passive activities. In a more recent observational study in a nursing home in the USA, Harper Ice (2002) estimated that residents spent 65% of their time doing nothing and 12% of the time in social activities. The findings from this study also highlighted the way that residents spend a great proportion of their days inactive, immobile or alone. In other words, participating in passive activity.

When some of the residents were alone they were not necessarily doing nothing, which is the impression gained from the literature. They were taking part in those activities that they found fulfilling and some people, such as Anne and Edna, were being supported by staff, family and friends to do so. The care home staff were not always aware of the participants' activities, the danger being that they did not facilitate what the residents were attempting to do.

Having something meaningful to do

In recognition of the damaging effects of inactivity, such as boredom, loneliness, depression and low quality of life, supporting residents to take part in communal or self-generated activities is widely advocated (see DoH, 2001a in the UK). The findings from this study suggest that being active in itself has little meaning to residents other than filling in time. The eight older people told of the value that they attached to those activities whereby they were engaged in doing something that was meaningful to them. In each of the case reconstructions in chapter 5, there were descriptions of activities that were meaningful and purposeful to the individual, such as Anne's weekly telephone conversation with her son, Charles going out with his friends, and Edna's exercise routine. Others told of what they would have liked to do but were

unable. Being able to engage in meaningful activity mattered to them. Whether they were able to take part in those things that they found fulfilling affected their life in the care home.

In Reed et al's (2003a) review of the literature of what older people view as health in later life and what they thought would achieve this, being able to participate in meaningful activity and adapting their goals to their circumstances were important to older people. This literature review and the accompanying empirical work highlighted areas for further research, such as what makes an activity meaningful.

The participants described a range of activities that had meaning for them. Some of these activities provided a means for the individual to stay in contact with family and friends, others represented continuity with past activities that the individual enjoyed, and others provided the means for them to maintain abilities. What these diverse activities have in common is the way that they were the means for the older person to fulfil objectives that they determined and considered to be important.

Being able to take part in meaningful activity

All of the participants were able to describe in detail what they would like to do, yet some fulfilled their wishes and others did not. A number of factors influenced this. Amongst these the individual's abilities, their approach to life in the care home and the resources that they could draw on were important. These factors were similar to the components of healthy aging identified by Bryant, Corbett and Kutner (2001). In this study, older people's views and definitions of healthy aging were examined. In the model that the team developed, an older person evaluated their abilities in terms of whether they were able to do certain things. The second component concerned the older person's willingness *'to go and do something'* and the third concerned the social and material resources that were available to support them to do what they chose.

By drawing on Bryant, Corbett and Kutner's ideas, the factors that influenced whether the participants were able to do what they wanted or not becomes more apparent. For example, Harriet wanted to knit some baby clothes for a member of staff (see p.165). Though her sister provided the necessary equipment and materials she lacked the physical dexterity to knit the garment. In the story retold by Florence's use of her patio as a garden (see p.209), she described the way that she used her financial resources to pay for a private carer and this person developed the garden under her instructions. Anne's carers assisted her to buy the budgies that gave her so much pleasure (see p.124). Edna continued to use her manual wheelchair, thereby using her remaining abilities to move herself despite the staff continuing to ask if she wanted an electric wheel chair (see p.101). Though all of the participants had limited physical abilities, in circumstances where they reshaped their goals and used their resources (e.g. staff support, family/friends support, financial resources to buy further assistance) they were able to participate in meaningful activity within the care home.

In summary, some of the older people in this study led lives that mainly involved passive activities, with long durations spent doing things to pass the time of day. Others were active in the way that they reconstructed the definitions that they held of meaningful activity. Some were innovative in their use of the resources that were at their disposal and this enabled them to bring their ideas to fruition. Though the care home staff were aware of some of the activities that these residents participated in, there were many facets of their life that took place unnoticed and, in this case, unsupported.

Narrative theme 6: Having an enriched private life / an impoverished private life.

Living in context

The multiple roles that individuals fulfil throughout their lives add both richness and the opportunity to express one's individuality in many different ways. Hepworth's (2000) book entitled 'The stories of ageing' dispels the notion that

self-expression is minimized due to role-reduction in later life. Roles change as individuals leave the workforce and take on new stations in later life. The circumstances of the move to a care home, which have been previously discussed, involve relocation of living arrangements and the transition to new roles. For some of the participants - Beatrice, Charles, Doris, Edna and Florence - the role of being the cared-for-person was alien to anything that they had previously known. Whilst Anne, Gloria and Harriet had received care prior to the move to the home, they experienced different levels of dependency that threatened their ability to attend to some aspects of self-care. With each stage of declining health and increased frailty came new, unfamiliar roles.

The context that the participants found themselves in following their transition to being a resident structured much of their days. Within this structure they were free to make choices about the way that they lived their lives within the choices that were available to them. They were able to participate in the communal, public life of the home. In some homes, the wide range of communal activities provided choice to suit everyone's preferences, whereas the scope in other homes was limited. In addition to discussion of the communal life in the home, the interviewees spoke of their personal, private world. These discussions highlighted the way that older people continue to have multiple levels of existence that provide them with the opportunity to fulfil different roles within the context of a care home.

Having a single room as a place to retreat from people and activities in the care home, and being supported to access that space, was highly instrumental in expanding the participants' choice in the way that they lived. In their individual rooms they experienced some privacy, albeit with frequent intrusions. This was their private space where they could be themselves and do the things that had meaning for them. With the provision of single rooms in the care homes, the residents were able to develop a private life within an environment that was largely public.

Using space for living

The previous discussions (narrative themes 4 and 5) indicated that the participants' rooms were more than a retreat within the care home. This was a place where they could be intimate with life-long friends. Anne's description of enjoying a night-cap with her friend and watching 'Who Wants to be a Millionaire' (see p.121) captured the enjoyment that she experienced being with someone she knew. They worked hard to modify their rooms, thus making them a haven for the cultivation of their private life, if they were able to do so.

Their own multi-media equipment enabled them to engage with those things that they found stimulating. Charles continued to pursue his passion for biographies through the talking books. In contrast, Beatrice, who had enlisted the support of the cleaner to set the lounge television channel for the football match that she wanted to watch, experienced frustration and anger when it was turned over by staff who didn't even ask if anyone wanted to view the game.

Those that had access to a private phone found that it helped them to keep in touch with their family and friends. They were able to have private conversations that were not scrutinized by others. In this way, they continued to express themselves through a range of multiple selves that were only disclosed through interacting with different people in different contexts. Edna, for example, maintained her support of missionary work through discussions with her friends; and Anne made a public declaration of her involvement with her family through her weekly telephone conversations with them.

Others tailored or extended their private space to facilitate them to pursue their interests. This was graphically illustrated through Florence's use of her patio as a garden. Others had similar living arrangements; however, they had not been as industrious in creating a garden that attracted the local wildlife to visit throughout the day.

Through the changes made to the rooms in the care homes, the residents shaped environments that portrayed them as individuals. This was not a cosmetic change, for many of the participants the changes that they made to their '*home*' within the care home enabled them to continue to live out their private life and, by doing so, extend their range of multiple selves that could have so easily been reduced to a singe role of the cared-for-person.

Restrictions on a private life in a care home

The participants' living space, a single small room, placed restrictions on what they could do in the home. They carefully selected furniture, equipment and appliances that could fit into this area to make optimal use of it. In addition to size, some appliances and services were unavailable to residents (e.g. a private phone line) even though they would have liked to use these to enhance their life in the home.

Some of the participants had very restricted private lives. Apart from sleeping, and very personal activities such as bathing, they spent little time alone. Most of their life was lived in public in group situations. Beatrice, Doris, Gloria and Harriet spent most of their days in the lounge, usually with the same people. Doris elected to spend her time with her fellow residents (see p.138). Her stories suggested that she didn't like to be on her own for long periods of time. She preferred to be with other people and when she wanted to spend time on her own she knew that she could go to her room or sit in the foyer. As she was acting on her choices, it could be argued that she did not experience a restriction of her private life, she was simply doing what she wanted to do.

The other three women suggested that they had little choice in the way that they spent their days. They relied on the assistance of staff to attend to their personal needs, and this included being moved in their wheelchair. Their lack of ability to move independently was a powerful factor that influenced where they went in the home and what they did during the day. The staff positioned them in the lounge, and collected them at intervals from this location for meals, to attend to their needs or to take part in group activities. Rarely did they object to being taken to the lounge after breakfast, lunch and tea, and

when they did, the staff usually didn't fulfil their request to spend time alone. These people faced considerable restrictions on developing a private life in the home as a consequence of their limited personal abilities and lack of support from staff, family and friends.

In summary, being able to construct a varied life within the care home was really important to the older people who took part in the study. They welcomed the opportunity to choose to take part in the communal life of the home and they equally valued a private life in which they were able to foster their multiple selves that had long existed. Some were limited by their abilities and lack of support to live anything other than a relatively public life.

Conclusion

The narrative themes captured various aspects of life in a care home. Though they were discussed in this chapter as if they were separate entities, with different situations being attributed to each theme, in reality these narrative themes were different dimensions of a resident's life in a care home. How these themes played out in their life were highlighted through their stories of their daily experiences.

The notion that older people construct each of the narrative themes in an attempt to shape their life in the care home was inherent to the discussion. This challenges the idea that older people passively adopt the role of the care home resident who is the recipient of care. This certainly was the case for some of the participants. Others, however, worked to and succeeded in reconstructing their life in the care home. The following chapter builds on the ideas discussed in this and the previous chapter, and moves on to explore the notion that alternative biographies co-exist within the care home setting.

Chapter 8

Residents living biographically active lives – theory development

Introduction

The stories that were retold in earlier chapters portrayed the unique ways that older people live in care homes. These were intimate stories about symbiotic family interaction, friendship, grief and loneliness; achieving personal goals during the twilight years, meaningful activity and boredom; decline, fear of further loss of functional ability, seeking ways to continue to do things for oneself and dependency; and, struggles and accomplishments to exert control over life as a resident. These accounts opened up the resident world to reveal a world that is as diverse as the people who live there.

The stories also highlighted the way that these older people worked to preserve their sense of self within the complex social environment of the care home. In this sense, they were biographically active agents, shaping the lives that they lived. Whilst some individuals were more successful than others in doing this, they all strived to integrate their experience as a resident into their personal biography.

The supposition that residents are biographically active is explored in this chapter. This idea focuses attention on the individual's interaction with the social system in the home. This is a system that is created and maintained by those living in, working in and visiting the care home. The chapter begins with an examination of the ways that older people continue to manifest their personhood within a care home. This leads onto the proposition that being able to live an active biographical life in this setting is important to and valued by residents. The chapter ends in outlining those features of care home life that influence the extent to which older people live biographically active lives.

What was learnt through interpretation of the residents' stories?

The resident stories revealed the complexity of establishing a life and living that life within a care home from the perspective of the resident. The idea that older people work hard to become a member of the care home community has been reported in previous qualitative work (Reed and Payton, 1996; Davies, 2001a). This study adds to this body of work and focuses on the individual not only fitting into the community but striving to live within it.

The participants had no rule book to guide them as they made the transition to the care home, which was at a time of diminished abilities and considerable vulnerability. Consequently, they adopted diverse strategies to maintain relationships and interests from their former life, as well as aspiring to develop new relationships and engage in activities that mattered to them. Some were more successful than others in doing this. They were the authors or the co-authors (where they required the support of others) of their life as a resident. In much the same way as an autobiography is an authored version of a life, they were biographically active in shaping the experiences in their later life.

Some of the participants were less successful in their attempts to implement the strategies that they devised to shape this final chapter of their biography. These people lived within severe strictures and led monotonously routinized lives where they did little more than perpetuate their existence. They had little influence over the way that they lived, and their efforts were often undermined by practices in the care home and the actions of others. In this sense they were biographically inactive, with other people, mainly the care staff, dictating their daily life.

There are two central ideas that arise through the residents' stories. First, the standard biography of a care home resident being the passive recipient of care (that is biographically inactive) as the dominant representation of life in a care home has been brought into question. Whilst residents can live

routinized lives, other people are and continue to be biographically active following the move to a care home. In this alternative biography it is the individual's construction of the narrative themes that gives shape to the life that is lived in a care home. This is ongoing and takes place within the microcosm of the resident world and at the interface between the resident and staff world. These alternative models of care home life are discussed in further detail in the following section of this chapter.

Secondly, the findings highlight the way that residents can live very different lives in the same care home. This interpretation of life in a care home provides a different and complimentary perspective to much of contemporary theory, which point to interactions and processes at an institutional level being the key determinants of residents' well-being and quality of life (Nolan, Grant and Davies, 2001; Stanley and Reed, 1999). The findings from this study, however, indicate that interactions and processes at the individual level are also significant determinants of an individual's experience in a care home.

Different ways of being in a care home

Existing in care

Some of the participants were able to do no more than express in words their desire to live in a particular way. Where their views were not taken into consideration, and their daily life revolved around the routines and the regimes of the institution, they were doing what could be considered little more than existing. Without exception, those who lived this life wanted more than being attended to as objects of care.

Rigid routines and institutional practices persist in spite of the introduction of minimum standards of practice (DoH, 2001a), systematic and regular regulation and inspection of care homes (DoH 2001b), and an emphasis on assuring quality of care and of life in care homes (O'Kell, 1995; Day, Klein and Redmayne, 1996; Reed et al 2003b). Beatrice's story of being told that it was not her time to get out of bed for another two hours (7.30am) when she needed to pass urine, subsequently soiling the bed, highlighted the lack of

responsiveness to her needs and the rigid routines that she endured. Then, to add insult to her embarrassment and loss of dignity, she was scolded by the carer for what had happened. This and other stories provided evidence that routines, institutional regimes and poor practices remain. It was only following prolonged contact with the participants that they spoke of what happened to them in their daily life. In the main, these residents were reluctantly acquiescent to their circumstances. They disliked what had happened to them but they indicated that they felt that they were powerless to change their situation.

The image of *'existing in care'* can be found throughout the literature. It is an image variously described as the *'lounge-standard individual'* (Lee Treweek, 1996/7) or older people being portrayed as *'bed and body work',* the product of the work of care staff (see Eyers, 2000; Nolan, Davies and Grant, 2001; Paternity, 2003). For older people living in this way, the routines of care relentlessly strip away their identity. They may be alive, yet they no longer live life in its fullest sense.

This depiction of life does not fully represent all features of those whose lives were largely dominated by routine and regimented care. The same people told stories about situations where they had participated in their own care, made choices that influenced their life in the care home, developed meaningful relationships with other people, modified their own space in the service of their needs and enjoyed some facets of a private, personal life. Where and when this happened was sporadic and limited. This suggests that what happens during daily life in a care home is the result of a complex interplay between the older person and the social context where they live. These people believed that expressing and acting on their choice of care and lifestyle was largely beyond their sphere of influence, and their life was overshadowed by those who exerted control in the care home.

Living with care

Living with those who experienced routinized and regimented lives were other older people who had developed roles and ways of being in a care home that

were biographically meaningful. These people, though bound by the routines of care, reconstructed their life and they *'lived with care'*. The provision of care and assistance was the foundation for a life that was different to that which they had previously known, yet this was a life that was filled with different possibilities whereby they continued to experience pleasure and satisfaction.

Anne created a weekly schedule of visits from her friend and telephone conversations with her family. These activities facilitated continuity between the past and the present. Her room in the care home was her domain, where she was able to be herself and express her individuality. She engaged in reciprocal activities of giving and receiving in her relationship with her long-term friend and her much loved pet budgies. Charles developed new routines. Throughout his life he had moved to more sedentary interests as his physical abilities changed and in this way he experienced pleasure and fulfilment in accomplishing those things that he wanted to do. Florence exchanged her financial resources to purchase the additional care and support that she wanted to access within the care home. With her paid support she was able to continue to pursue her interest in gardening, design her environment to her satisfaction and visit the community that held cherished memories of her later adult years. They worked hard to create the life that they wanted to live as a resident by using a range of strategies and the resources that were at their disposal (see chapter 6).

Though these people lived in the care home and participated in the daily happenings in that environment, they also lived a life that they had reconstructed following the move to a care home. They selected when and how they participated in the community life of the home. This is an alternative biography to the one so often reported in the wider literature of older people being mere recipients of care. These older people continued to manifest their personhood during the final stage of their lives. The commentary by Barba (2002) on nursing home environments in America highlighted the important role of staff in creating a nurturing environment that enables residents to 'get pleasure from each day' (p. 5). This focuses attention on staff roles and

responsibilities. The evidence from this study points to the important but little recognized role of older people being instrumental in shaping their niche in the care home and optimizing the possibilities that exist for their life.

There is no suggestion that life was without difficulties for those who were biographically active in the context of a care home. Anne spoke in detail of the boredom and the loneliness that she experienced. Charles was saddened by the lack of companionship in the care home. Florence vehemently resisted the routines of attending to her bodily functions. These people, however, were able to continue to experience enjoyment despite their circumstances.

The life that the residents created for themselves was very fragile. The actions of staff, family and friends unwittingly undermined what these people had achieved (see p. 126, 188, 198). When staff were lacking in awareness of the older person's aspirations or they acted blindly but in good faith that they and not the older person knew best, then their actions quickly led to an undoing of the resident's efforts. This points to the importance of ongoing dialogue between the older person and care staff to assess needs and preferences, to ensure that the strategies that residents implement to shape their life are recognized and supported.

The things that mattered to Ann, Beatrice, Charles, Doris, Edna, Florence, Gloria and Harriet in their life as a resident

Everyday experiences matter

These people had moved beyond a stage where they could live an independent life and pursue their personal aspirations in the ways that they chose with minimal restriction. For the majority of these people decline in their physical health, functional ability and possibly mental health was inevitable. In their everyday life they struggled with physical decline. Though this led them to believe that they were reaching the end of their lives, they focused their attention on living until the time of their death arrived. What was important to them centred around their everyday experiences.

As they settled into their new home, they assessed and adjusted their expectations. Kahn (1999) made similar observations and concluded that frail older people reduce their expectations of life and attempt to '*make the best of it*'. They have a tendency to play down the negative aspects of life as a resident and minimize the significance of what they are no longer able to do. Kahn also found that older people concentrated on the important aspects of the life that they have lived, their experience of their present situation and what they could still master. This was certainly the case for Anne, Charles, Doris and Edna who initiated and negotiated a range of strategies that enabled them to do the things that they found pleasurable and fulfilling. They experienced enjoyment and attained personal satisfaction from doing the things that they wanted to do, and achieving the objectives that they set for themselves. In other words, they had a future that they could plan and they strove to achieve this.

Beatrice, Florence, Gloria and Harriet, however, did not play down the negative aspects of their life in the care home. Their case reconstructions, in chapter 5, highlighted their difficulties, disappointments and frustration as they put up with circumstances that they felt were beyond their control, and they continued to aim for goals that they were unable to fulfil. Whilst these people disliked many aspects of their situation and they felt that they had minimal influence over their daily experiences, this did not deter them from attempting to change things that they felt were within their sphere of influence.

What the participants experienced in their life as residents was the outcome of negotiations with fellow residents, staff, family and friends as well as implementing the strategies they devised to shape their life. In this way the residents exerted their influence over the areas of life that correlated with the narrative themes:

- what they could do for themselves and the degree of independence experienced
- being able to influence and control their life in the care home
- keeping and developing fulfilling relationships with other people

- having personal space in the care home that they used for their own purposes
- engaging in meaningful activity
- and living an enriched private life.

It was the interplay between the individual, context and circumstance that shaped the individual's experience of life as a resident and the outcome of this process mattered dearly to the participants.

Realising expectations does matter

Being able to realise expectations because of the care received mattered to the participants. In an exploration of the theoretical perspectives that underpin gerontological nursing practice to promote the well-being of frail older people living in nursing homes, Bergland and Kirkevold (2001) drew on the theory of thriving developed by Peterson (1995, 1997). In this theory, thriving is viewed as an emotional state. Individuals are active agents who assess the expectations that can be met in their environment and those that cannot be fulfilled. According to this theory, thriving results when an individual takes action to get what they want and chooses not to have what they cannot obtain. The precondition to optimum well-being, therefore, is acknowledging expectations and making judgements about the possibilities of realising those expectations. In addition, well-being is optimized if an individual chooses to adjust their expectations according to what the social circumstance offers.

This theory provides a framework for the different evaluations that the participants held about living in a care home and the outcomes they attempted to achieve. If their set of expectations included the notion that they would be supported to do as much as possible for themselves, and they were able to realise this, they experienced satisfaction and fulfilment. For example, Edna spoke of the importance of being able to self-medicate in the care home (p.146) and perform her daily exercise routines (p.145). Conversely, she was really frustrated when she was unable to convey to the staff the importance of continuing to use a manual wheelchair to enable her to move her chair using

her remaining leg (p.101). Here, she was concerned that she would unable to realise her expectation that she would be supported to undertake activities that she believed maintained her independence. This illustration highlights the importance of recognising and responding to the strategies that residents develop to enable them to fulfil their aspirations.

Living a biographical life, when living with care, matters

Individuals differ in their aspirations, preferences, backgrounds and experiences. It is this individual variation that contributes to the rich social tapestry that exists in society. Though care home residents have a common need for assistance, care and support, individual variation with respect to all other aspects of life remains.

The individual stories (chapter 5) and narrative themes (chapters 6 & 7) indicate that residents derive pleasure, a sense of purpose, satisfaction and fulfilment in different ways. What is important to one person may be different to the next. A unifying theme across all of the stories was the importance of the individual being able to determine what they valued and being able to achieve the things that mattered to them. They wanted to achieve this in addition to receiving good quality care. Hence, the care that they received provided a foundation that enabled them to satisfy their desires and optimise their capacities. It can be concluded from this that older people who live in a care home want to live with care, which provides a supportive framework for their life.

The argument has been developed that it is daily experiences residents evaluate in their construction of the narrative themes and this process shapes the biography of an older person in their life as a care home resident. In this sense, the narrative themes have been conceptualised by the researcher as dimensions of care home life. The participants wanted to live their life in a particular way and those who were successful, to a greater or lesser extent, in achieving this lived '*a biographically active life*'. This term is used to describe a way of living in a care home where older people are enabled to do something for themselves, make choices and plans for the future, experience

fulfilling relationships, have their personal place in the care home and do something meaningful that mattered to them. Though frail older people experience many physical, sensory, emotional and social difficulties, the capacity to develop strategies to tailor their life to their preferences remains. Life as a care home resident does not have to be reduced to a biological existence; it can have meaning if the individual is enabled to live a biographically active life.

Living within the care home community

During the process of relocation the participants knew that they were moving to a care home, however as they settled in they also knew that this place could never be their home. Staff, family and friends reinforced the idea that the place that they had moved to was *'now their home',* yet everyday experiences reaffirmed their understanding that they were living in a home that would never be their own. This distinction between living at home and living in a home was discussed in chapter 2 (p. 35). Here the existential and experiential dimensions of home as representative of personhood, and symbolic as a place of refuge, security, independence and personal autonomy, was highlighted (Sixsmith, 1990; Heyman, Oldman and Means, 2002; Maddox 2003). Though the participants actively personalised and modified their rooms and their proximal space (see narrative theme 4, p.208) these intrinsic dimensions of their own home were lacking in the care home.

The care home was not like home to residents, yet they realized in another sense that it was their home. It was their residence and the place that provided shelter, care and support. It was also the place where they were a resident who lived with many other residents, cared for by staff and visited by family and friends. In this sense they were living in a home that was also a community.

Recent empirical work by Davies (2001a) has contributed to the development of the idea of a care home as a community, with each community creating its

own distinctive climate (see p.29). Davies and Brown-Wilson (2006), in a review of the literature, developed the model of care home as community and explicated the way that the community in a care home (residents, relatives and staff) reflects a set of values, and it is this culture that determines the experience of life and work within a particular setting. The findings presented in chapters 5, 6, and 7 challenge the notion of the culture of the care home being the sole determinant of a resident's individual experience. All of the participants had very different experiences. In particular, the contrast between Anne and Beatrice, who lived with each other, and Edna and Florence, who also lived with each other in a different care home, point to the possibility that something more than the prevailing culture of the care home community determined their life as residents.

This is not suggesting that care home culture is unimportant. The evidence within the field of care home research, and other fields that have examined the impact of institutional processes on those who live long-term in group care settings, has demonstrated the powerful influence of culture (see p. 20-24). This analysis, however, views the culture of a care home through a macro lens and suggests that a particular culture is all pervasive, shaping the lives of those who live in that setting. The evidence from this study is derived through a micro lens, from residents' views of the world that they live in. These findings point to interaction at the individual level of existence within a care home as a determinant of the experience of individual residents. The following discussion develops these ideas and presents a conceptual model that may lead to a more sophisticated understanding of the complex dynamics within the care home community that contribute to older people living in a normal and meaningful way for them.

A conceptual model of residents living biographically active lives

The experiences that lead up to moving to a care home and the initial encounters there are extremely important in influencing an older person's understanding of what life could be in a care home. From the interpretations that were presented in chapters 5, 6 and 7 it is clear that the immediacy of receiving care and living a different lifestyle is clearly evident to older people as they move into a care home.

The circumstances of the move are a powerful influence shaping their perceptions of care home life beyond the move itself. In the early days, older people are acute observers of the interactions between residents, staff and visitors to the home that they now live in. Though verbal interaction can (re)shape their perceptions, what is inferred through non-verbal communication and subtlety, what is left unsaid is equally powerful. These interactions and observations set the stage for the older person of the possibilities of living in a care home. Some people construe this as the opportunity to fulfil aspirations as a result of the care received, whereas other people contract their expectations to little more than being a recipient of care.

Residents know from their early encounters in a care home that their days are organised by relatively set routines. Whilst acknowledging the need to adapt to a new rhythm of life, they continuously adjust their expectations of care home life and build on the perceptions that they established during their early days in the home. Throughout the process of settling into the home, residents begin to construct their experiences of each of the narrative themes. Where this construction develops into possibilities for self-care, being in control, meaningful relationships, active use of place, engaging in meaningful activity and having a rich private life the dimensions for living a biographical life are established. This process of constructing their experience of the narrative themes continues throughout the resident's lifetime in the care home.

The interpretations presented in chapters 6 and 7 indicated that an individual's experiences of life in the care home shaped their construction of each of the narrative themes. This discussion also highlighted the way that practices and processes within the care home community influenced individual experience. The impact of the climate of a care home on individual experience has been the subject of much discussion in the care home literature, and this is a central tenet of the model of care home as community within Davies' (2001a) and Davies and Brown-Wilson's (2006) work. This theory points to the existence of different types of climates in care homes, with the complete community being consistent with the most positive resident experience. In complete communities there is an emphasis on providing enabling, supportive and restorative long-term care (see p. 29 for more detailed discussion). These authors argue that relationship-centred care is provided in complete communities and this enables older people to experience fulfilment in each of the senses identified in the 'Senses Framework' of Nolan et al (2001, 2002, 2004), that is experiencing a positive sense of security, belonging, continuity, purpose, achievement and/or significance.

In many respects the model of care home as community and the alternative biography of residents as active biographical agents are highly compatible. Elements of the care home as community model resonate with the narrative themes. With the exception of 'caring for oneself / being cared for', and 'having an enriched private life / an impoverished private life' - there is a correlation between the other dimensions of care home life that are addressed in both models. There are, however, differences. In the care home as community model, the concern rests with the collective living aspect of care home life, whereas resident experience is the key concern in the model of residents living biographically active lives. Though there is interplay between these models, they are distinct.

Clearly, what happens at the level of the community in a care home does impact on the lives of its members. Equally, the individual members of that community can influence the way that the community functions. These

ongoing complex interactions between the various parts of the social system within a care home have been captured by Anderson, Issel and McDaniel (2003) in a cross-sectional field study carried out in American nursing homes. This research team explored the impact of management practices on resident outcomes and utilized complexity theory to explain why certain management practices work better than others in different situations.

In Anderson, Issel and McDaniel's (2003) study the nursing home was conceived as a complex self-adaptive system. The people within this system constantly adjust their behaviours in response to changes within the system. For example, when staff fail to arrive for rostered duty, the remaining staff adjust their priorities and modify their activities to ensure that the available staff team is best placed to respond to the needs of residents within existing resources. In this sense, the social system of a care home is self-organizing, and it is the connections and interactions between people, processes and organisational structures that determine what occurs in a particular care home environment.

In Anderson et al's study the focus of interest was on behaviours that were carried out in the staff world of a nursing home and the impact of those behaviours on resident outcomes. In this conception of the nursing home, the interactions between residents, and between residents and staff, and the self-adaptive responses of these people to their interactions were not considered in the analysis of the findings. The growing body of literature that highlights the impact of the interaction between these groups of people in determining quality of care and quality of life outcomes points to the importance of considering all stakeholders within the system as capable of self-organizing behaviour, and therefore capable of influencing the system itself (Grau and Wellin, 1992; Grau, Chandler and Saunders, 1995; NCHR&D Forum report, 2006). This has been reinforced throughout the interviews with residents in this inquiry where they told stories about ways that they interacted with others living, working or visiting the care home, and modified their behaviours in response to the actions of other people or their communication with them.

The theory of self-organization within complex adaptive systems offers an overarching framework for the integration of the influences of the care home community and those of individuals as determinants of the individual resident's life experience. Within the self-adapting system of the care home many internal factors are constantly changing - the people who live and work in the home alter continuously; the condition of residents either improves or deteriorates; what residents want to achieve and what they can do are also in a permanent state of flux; the organisation of care exposes residents to different practices as different staff work throughout the day; and management practices are also diverse. These represent only a few of the extensive range of internal factors that exist in this complex social environment.

External factors are also powerful influences on what occurs in an individual care home. Health and social care policy, regulatory practices, market forces, societal expectations of long term care for older people, demographic trends and workforce issues all impact on the experience of the older person. Hence many factors are present at any given time within care homes. As these interact with each other, a chain reaction is set in motion leading to a response elsewhere in the system. The response itself is self-organising. Thus, ongoing change is perpetuated within the social environment of the care home.

It is the dynamic, complex interplay between person, context and circumstance within the care home system that the model presented here captures. These complex ongoing interactions are considered central to determining whether an older person is enabled to live a biographically active life in a care home or not. This is illustrated diagrammatically in figure 8.1. Here the way an individual resident experiences each dimension of their biographical life is depicted as the product of their construction of each of the narrative themes, which are shaped by a range of facilitating and moderating factors within given contexts and circumstances, and by the strategies that the older person and staff execute in their daily activities. This is a complex

interaction that is constantly changing the individual's understanding of each of the narrative themes.

The left-hand column of the model presented in figures 8.1 and 8.2 is representative of the range of facilitating and moderating factors within care homes that influence an individual's experience of living in that environment. The influences that are included in the figures were derived from an examination of the care home literature, which took place during the development of the bibliographic overview and the critical in-depth phase of interpretation (see p. 106-111). This aspect of the model is elaborated in the next section of this chapter. The central column represents the older person's construction of the narrative themes as they progress through the various stages of moving-in, settling-in, living-in and moving-on from the care home as described in chapter 6.

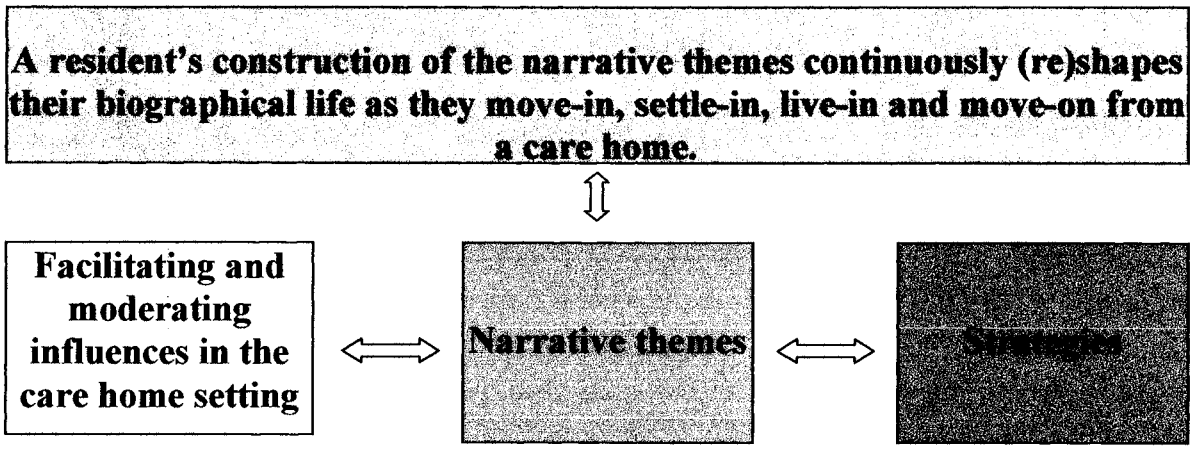
The right-hand column of the model represents strategies that different populations within the care home setting adopt to shape the life that is lived within care homes. There are three types of strategies included in the model:

- resident-led strategies represent resident-led decisions and activities that were described in the typology presented in chapter 6 (p.190-191). For example, Doris identified the role of door opener for the morning staff for herself that enabled her to experience a sense of purpose within the care home.
- negotiated strategies are those resident-negotiated activities that were described in the typology presented in chapter 6 (p.190-191). For example, Charles negotiated his travel arrangements with his friends to enable him to enjoy a night out of the home with them.
- staff-led strategies refers to staff behaviours and practices within the home that specifically influence a resident's construction of one or more of the narrative themes. For example, Edna's personalized activities program that was arranged by the activities co-ordinator enabled her to dictate letters to care staff for her friends, and the residents committee that was established by staff to give residents an

opportunity to voice their opinion about day-to-day events in care home A. Though staff actions and behaviours are identified in the left-hand column and represent the practice literature concerning this subject, staff-led strategies are included in the right-hand column to portray specific interactions and practices that influence residents' construction of the narrative themes.

The diagram that represents this model of care home living (figure 8.1), and the later elaboration of this model (figure 8.2, p.229), appear to present this process as more linear than the data would suggest. These diagrams are an attempt to simplify and clarify the process and in doing so have been unable to pay attention to the complexity, continuity and the circularity of the process that shape an older person's experience of life as a resident in a care home.

Figure 8.1: Diagrammatic representation of dimensions within care home life that influence an older person in their construction of their experience of care home life



The complex interactions that take place in a care home are illustrated in the following example. Throughout the earlier chapters there has been discussion of Edna's attempt to continue to care for herself and optimise her independence in the care home setting. Her construction of the narrative theme 'caring for oneself/being cared for,' however, played out in different ways in different situations. Her strategy of devising and carrying out an exercise programme with the aim of maintaining her dexterity and physical

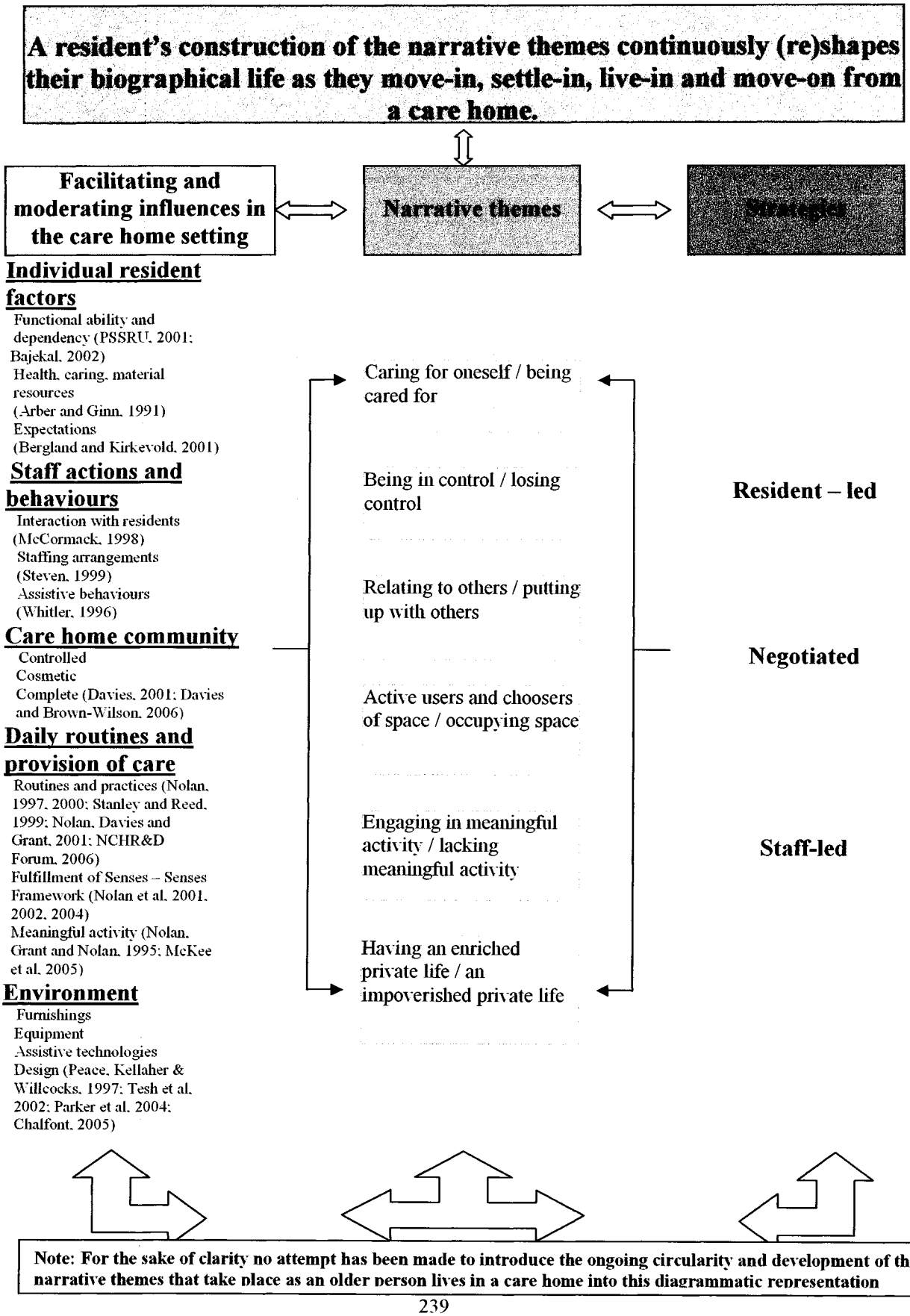
abilities was facilitated by the privacy that she experienced within her private room. Equally, being able to self-medicate was facilitated by the staff who ensured that there were facilities to lock her medication in an accessible place in her room. These are both examples of the way that she and was enabled to construct her life in the care home to be able to continue to care for herself and in this way experience a sense of independence. In contrast the strategy of continuing to use a manual wheelchair in order to maintain the movement of her remaining limb was challenged and undermined when care staff pushed her chair without asking if she wanted assistance. Their actions, though well-intentioned limited her experience of self-care.

The narrative themes and strategies have been discussed in detail in chapters 6 and 7, whereas some of the facilitating and moderating influences in the care home setting have only been identified up to this point, so these are explored in further detail in the following section of this chapter. The model presented here provides an explanation for the observation that older people are more or less biographically active in different dimensions of their life, and at different times in response to diverse influences in a care home.

Influences that facilitate or impede residents' living a biographically active life

Though numerous factors influence individual experience, particular categories consistently surfaced when the older people discussed their lives. At the risk of oversimplification the categories were factors associated with the individual resident's resources, the culture of the care home, daily routines and provision of care; actions and behaviours of staff; and the environment of the care home itself. These are illustrated diagrammatically in figure 8.2, and, with the exception of the care home community that depicts the culture within a home, which has been discussed previously, each of these categories are briefly discussed to highlight their potential influence on resident's living an active biographical life.

Figure 8.2: Diagrammatic representation of dimensions within care home life that influence an older person in their construction of their experience of care home life (detailed model)



Individual resident factors

A consistent message that has threaded throughout the discussion is the diversity within the resident population. Residents are older people who have different abilities, capacities, health status and expectations (Campbell, Jagger and Clark, 1993, Bergland and Kirkevold, 2001; PSSRU, 2001, PSSRU, 2001; Bajekal, 2002) and these manifest in their individual approach to care home life. The analysis pointed to the way that the participants made continued efforts to reframe and reconstruct their life as a resident. This was particularly important because their functional abilities and health status fluctuated and their personal circumstances changed. In response, they drew on a range of strategies to shape their daily lives.

As the study progressed the idea developed that those residents who adopted strategies that they could carry out themselves or could engage the support of other people to do so, were effective in recreating their biographical life in the care home. They did this in spite of declining health and increasing frailty. Physical ability, therefore, may have an influence on an individual's ability to live their life but this is not the overriding determinant of the way that an individual lives in a care home. Where the individual initiated and was able to implement a strategy that they had devised, their efforts were more likely to be effective.

In the majority of situations, however, these older people needed the agreement or support of others to enable them to live their life in a particular way. For example, Charles' insistence on moving to a home in the locality he had lived most of his life, increased the likelihood of maintaining contact with friends and being able to arrange a social night with them. To move to his preferred care home, he required agreement from different people. First, he stated his preference to his care manager, which started a chain of negotiation with care home staff. Following the move to the care home he was reliant on the support of the staff to assist him to take part in a weekly night out with friends and on his friends' willingness to arrange the necessary transport.

Whilst an individual's abilities are an important influence in determining what they can and cannot do, the different types of resources that older people have at their disposal impacts on their potential to effect the strategies that they develop. Everyone has different resources at their disposal. In order to capture this diversity and range, the discussion will draw on the concept of the *'Resource Triangle'* that has been developed by Arber and Ginn (1991). They proposed the idea that older people have different resources that they use interchangeably to support them in later life. These are health resources (including physical abilities as previously discussed), caring and material resources.

Caring resources, according to Arber and Ginn, include the support of family and friends. Throughout the resident stories this type of support was instrumental in enriching the type of life that was lived in the home. Maintaining contact with these individuals enabled the older person to be socially engaged with what was happening outside of the home. These people often provided the equipment or resources for the resident to pursue interests that they found fulfilling. More importantly, these relationships provided a source of intimacy that was often lacking in the relationship that they had developed following the move to the care home.

Material resources include accommodation, possessions and income. On entry to a care home older people face substantial stripping in terms of their personal possessions. The evidence from this study (and many others) highlights the value that older people attach to the possessions that remain with them. These resources are used to signify personal identity in a foreign environment, a link with a past life, and maintenance of their life within new living arrangements.

Financial resources are a major concern to residents. For the participants who had a limited income or no longer had an independent source of money, they felt vulnerable and worried about the future (they were particularly concerned about the time when their personal financial resources could no longer meet

the cost of their care). Others had substantial monetary resources that they were able to draw on. Within the concept of the Resource Triangle there is the notion that different types of resources can be exchanged. For example Florence exchanged the financial resources at her disposal to secure the caring resources that she required to enhance her life in the care home. This notion, when applied to the model of older people living biographically active lives enhances the possibilities for the older residents in devising strategies and carrying them out.

Daily routines and provision of care

Residence in a care home invariably involves loss of privacy, fixed schedules, loss of some choice and uniformity. When everyday routines are constantly the same, residents experience monotony and boredom. Rigid routines can be a barrier to residents living the way that they want to live and being able to fulfil their expectations. At worst, living with fixed and rigid routines can result in negative and degrading experiences (see p. 223).

Residents do not always perceive routines and provision of care as negative (Nolan, 1997, 2000; Stanley and Reed, 1999; Nolan, Davies and Grant, 2001; NCHR&D Forum, 2006). Being able to predict what happens in a care home and when daily activities occur can provide a sense of security to residents. In the development of the 'Senses Framework', Nolan (1997) highlighted the importance of 'A sense of security' as a necessary condition for older people feeling safe and free from threat, harm, pain and discomfort. Throughout the residents' stories they spoke of the routines of the care home being a backdrop to their life. Knowing that members of staff who they trusted and liked were working on a particular day was comforting. In addition having set days for visits from family and friends ensured that there was something that they could look forward to, and something that broke up the routines that dominated most of their days.

Daily routines in the care home also created opportunities for the residents to fulfil roles that they had developed in the care home. Doris, for example, ensured that she was ready for the day in time to sit in the foyer and open the door for staff arriving for the morning shift. In this way, she opened the door, enabling the night staff to continue to attend to residents without disturbance, whilst also greeting the arriving staff (p.138). This was an important role she assumed and one that contributed to the life of the care home. Davies and Brown-Wilson (2006) highlight the importance of residents being able to experience '*giving and receiving'* as a member of the care home community. They argue that reciprocity in relationships is essential to the well-being of residents. Reciprocity can manifest in many ways, not least fulfilling roles within the community. Finding these opportunities for frail older people can be difficult, yet when residents do carry out roles they can achieve what Nolan (1997) refers to as a '*Sense of purpose*.'

Being able to take part in meaningful activity was an important dimension of biographical activity to the residents. They all took part in 'time-filling' activities and the necessary routines of daily life; however these were viewed as the means to do what they considered to be enjoyable and meaningful in the contexts of their life. There is increasing evidence that those activities that residents perceive to be meaningful promote the well-being of frail older people (Voelkl, Fires and Galecki, 1995; McKee et al 2005; Zimmermann et al, 2005). The residents' stories indicate that meaningful activity was the result of considerable effort by residents, staff, family and friends working together.

Daily routines and provision of care, as described here, are important influences on the way that residents live. Older people acknowledge that there is need for routines and daily practices for the smooth functioning of the communal environment. They also desire the freedom to negotiate space within these routines to live their life. This requires a degree of negotiation between residents, and between residents and staff, to ensure that there is a balance between the preferences of individuals and the need of the group of residents within the care home community.

Actions and behaviours of staff

The case reconstructions and the discussion of the narrative themes indicated that care staff are a rich resource for older people in their efforts to reconstruct their life. Both residents and staff highlighted the importance of staff developing an in-depth and intimate knowledge of the older person. The continuous interaction that occurs throughout the day between residents and staff provides opportunities to learn more about each other. By '*getting to know*' the residents, care staff become aware of the older person's need, preferences and their actual or potential problems. Such information is generally regarded as the foundation for individualized care and the provision of people-centred services (Williams & Grant 1998; Nolan, 2000). As care staff become familiar with a resident's pattern of behaviours, they notice the subtle changes that continuously occur, and if they respond accordingly care is constantly fine-tuned.

Staffing arrangements and the management of care can have a significant impact on the degree to which residents and staff get to know each other. Team work arrangements, named nurse allocations and key worker systems facilitated the same people working with the same residents (Shannon, 1998; Pontin, 1999; Steven, 1999). Though these practices were operating in the care homes, the participants' spoke of the way that staff were constantly coming to or leaving employment in the home (see p. 119, 124 & 129). The transitory nature of the staffing community negatively influenced the extent that staff and residents developed understanding of each other.

Though there was evidence that staff were supportive and responsive to the residents' needs, there was also evidence that staff did not always act in this way. The participants needed to negotiate day to day aspects of care and lifestyle, and this required constant review and negotiation. These people were disadvantaged by health problems that potentially limited their participation in decision-making about their care. Problems, such as restricted sensory abilities, made communication difficult, while problems such as reduced mobility and functional capacity increased their dependence on others in a

range of activities which are usually carried out autonomously. Hence they required support from staff, first, to recognise their particular difficulties, secondly to act in ways that enabled them to take part in decision-making, and thirdly to support them to carry out their decisions (Whitler, 1996).

In the business of everyday activity, customary practices dominated the way that care tasks were carried out in the care homes. Though staff discussed individual preferences and choices with residents this was not always translated into practice. Evidence from a range of studies has consistently highlighted the difficulties that older people continue to encounter in negotiating their care and lifestyle choices with care staff. The importance of communication, negotiation and respect for an individual's values in the assessment of need and the establishment of care plans has been identified, yet this remains problematic (Kaakinen, 1995; Health Advisory Service 2000, 1998). McCormack's (1998) qualitative study identified a range of attitudinal, organisational and conversational barriers between older people and carers that act as constraints on the older person's capacity for participation in their care and a lack of ability among nursing staff to negotiate the boundaries of care decisions. These studies stress the importance of staff engaging with older people in a way that places them at the centre of all decisions that affect their life. Such an engagement would require staff to adopt an approach to practice that does not see older people as problems, but instead as residents with a right to make decisions about their needs and lifestyle choices.

Environment

The physical environment of the care home is as important a determinant of the degree that older people can live a biographical life as the other factors that have been discussed. Anne's story of the refurbishment of the care home that she lived in (p.198), is a poignant example of the significant impact that environment can have on the lives of residents. Environment is generally regarded as an important contributor to a sense of well-being and quality of life (WHOQoL Group, 1998). This notion has underpinned the discussion

within the professional literature that points to the importance of transforming the design, physical structure, fabric and furnishings of care homes in order to create human habitats where residents can thrive in their latter years (Parmalee and Lawton, 1990; Peace, Kellaher and Willcocks, 1997; Tesh et al 2002).

There are various dimensions of environment that are important to residents. Reed's (2006) discussion points to the dimensions of aesthetic appeal, comfort, and safety. There has been considerable effort devoted to enhancing these dimensions of the built environment in recent years in the UK. As care homes are newly built or refurbished proprietors work toward ensuring that the fabric and design of the building is appealing to existing residents, potential occupants, family and friends. The importance of the aesthetic appeal of an environment was captured in Anne's description of her son's and friend's impressions of the care homes that they visited. Their first impressions were crucial factors in discounting a care home as a potential place of residence for Anne, or suggesting that she moved to the home. What the home looked like, its design, decor, ambience and odour were critical factors that shaped their impressions about the suitability of the place as a residence and the possibilities for living in that environment.

Comfort is a dimension that Reed suggests includes personal preference and functionality. The participants also spoke of the care home as being '*comfortable*', a place where they felt at ease and as a place where they experienced an adequate standard of living. This understanding of comfort is synonymous with dictionary definitions of the word comfortable (see Collins English Dictionary, 1999). Whilst being comfortable was important to their everyday experience, they stressed the importance of tailoring personal space to one's own preferences and optimizing the functionality of that space as captured in the dimension of biographical living represented by the narrative theme 'Active users and choosers of space / occupying space' (p. 208). The participants referred to these aspects of their environment as very separate qualities that were equally important.

Being able to personalise their space enabled them to express their personhood, and maintain their links with the past. In contrast, modifying personal space to enhance its functionality has instrumental value. By adapting an environment, residents are enabled to do what they want to do. As a consequence of frailty and limitations in functional ability, however, residents are less able to make adaptations to their environments. Hence, they require support to do this. There is the potential for care staff to play a significant role in facilitating residents to adapt their environments. They can initiate discussions with residents to identify need and to make the necessary changes to their environment. As assistive technologies, housing adaptations and supportive furnishings become available; staff can discuss the utility of these with individual residents.

Involving residents in discussions about design and refurbishment of a care home is as important as discussions about their immediate personal space. There is evidence from initiatives that have involved older people with housing design and housing policy that suggests their views of design and adaptation do differ from the views of professionals (House for Life, 2001; Reed et al 2006). Older people make decisions about adaptations to housing that are grounded in their understanding of the impact of their environment on their ability to undertake self-care tasks and those activities that they find meaningful. When environments are changed without consultation with residents, there is the possibility that the environment may not meet their needs and may have a negative impact on their lifestyle.

Personal and communal spaces in care homes have a significant influence on relationships between those living and working in that environment. The design of communal spaces can facilitate interaction between people as they meet each other during daily activities. Davies' (2003) research highlights the importance of conversations in passing. Also, Reed and Payton's (1996) findings pointed out the way that seating arrangements in the communal areas of care homes influence relationships between residents. The residents' personal space as a place where they met friends and family in private and enjoyed intimate times was evident throughout the case reconstructions.

This discussion would not be complete without reference to the environment where a care home is located (Parker et al, 2004; Chalfont, 2005). The location of a care home is a significant factor in the biographical life that an older person lives. Continued interaction with friends and family is highly dependant on them being able to access the care home. In this sense, linkage with local public transport and accessible roads is important. Interaction with the local community is facilitated if a care home exists within a community. However, a care home can also be isolated within a community if interaction with that community is not fostered. Environments are more than a physical dwelling, they are places that need to be created to enable older people to thrive within them.

Conclusion

The findings from the study have highlighted the way that residents are active agents in reconstructing their lives in a care home. Some individuals are more successful in their attempts to do this than others. Their efforts and their struggles to embed their life in a care home into their personal values, goals, history and life experiences can contribute to the creation of a life that they consider worth living. This does not happen in isolation. There is a complex interaction between a resident's context and circumstance which has powerful influence on the way that an older person lives. This is represented by the conceptual model of residents living biographically active lives that was presented in this chapter.

To live an active biographical life, resident's efforts need to be recognised and the strategies that they devise supported by other people. This does require rethinking the notions that people hold of care home life, to see possibilities for living that exist beyond ensuring that the right amount of care is available at the right time for the older person. This is only the foundation that an older person may build on to live a different life, yet a life that they value.

Chapter 9

Conclusion: Living a life is possible in care homes

Introduction

This study makes a distinct contribution to current understanding of care home life by pausing to listen to what older people say about their lives as residents and, importantly, hearing what they have to say. The voice of the older person has been almost inaudible in the increasing literature about the lives that these people live in a care home. This inquiry was therefore designed with the explicit aim to meet with care home residents and develop a shared understanding of their lives, their views and concerns. Though many of the stories that have been retold are simple accounts of what happened to older people, they poignantly portrayed the efforts of older people to continue to live a life that was meaningful, and had purpose and possibilities for enjoyment. Their struggles were often hidden in the personal and sometimes isolated world that they lived, the danger being that their efforts were sometimes unsupported and, at worst, undermined.

The final chapter in this thesis reflects on the meaning and implications of the stories that were retold of life in a care home. The chapter commences with an examination of the ways that older people can continue to manifest their personhood within a care home setting. It concludes by examining the implications of the knowledge gained through the study for theory and practice development.

Older people want to live with care

When older people move to a care home they have experienced many changes that collectively contribute to this being a major life transition. The

move itself is a process rather than an event whereby the older person adjusts to life as a resident (Tobin and Lieberman, 1987; Guthiel, 1991; Patterson, 1995; Nay, 1995; Reed and Payton, 1996). The findings from this study suggest that the process of adjustment is not straightforward and continues well beyond the phase of settling into a care home.

Older people enter a care home with a set of expectations that are reviewed and refined as they interact with the resident and staff communities, and experience the happenings within those communities. As they settle into and live in a care home they attempt to make sense of the complexities of daily life, which shapes their construction of each dimension of biographical living, as represented by the narrative themes (see chapters 6 & 7). These constructions influence the way that an older person attempts to continue to care for themselves and express their independence in a highly dependent environment; make and act on their choices; relate to fellow residents, family, friends and staff; modify their personal and communal space in the service of their needs; engage in activities; and develop different facets of living within the care home community.

Residents do, however, have physical and cognitive constraints that limit what they can do, yet they want recognition for what they can mentally, physically and emotionally continue to do. Though residents experience limitations, they develop a range of strategies with the aim of influencing the life that they live. Where they are able to implement those strategies, by themselves or with support, they reconstruct their life in ways whereby they live with care as illustrated in some of the case reconstructions in chapter 5. This is a dynamic process that takes place within the microcosm of the resident world.

The interpretation of the residents' stories presented in this thesis suggests that older people want to live life in the most natural, normal and meaningful way possible. In other words older people who require long-term care need care, but they want this to provide the foundation on which they build a life in a care home that is meaningful in the context of their personal biography. This

has been described throughout this thesis as a life whereby residents '*live with care*' (as defined p.224).

The evidence indicates that residents can be biographically active, whereby they work to reconstruct their life in a care home. The conceptual model presented in chapter 8, of residents living biographically active lives, portrays the complex interplay between individual, context and circumstance that influences the way older people live with care. This model offers an explanation for the observation that older people can be more or less biographically active in different dimensions of their life in a care home. For example, they may engage in meaningful relationships with other people yet experience limited control over what they do and how they do those things. In circumstances where the individual is largely biographically inactive in the majority of the dimensions of their residential life, this way of living has been described here as '*existing in care*' (as defined p.223).

Overwhelmingly the older people in this study wanted to live with care, which held for them possibilities for enjoyment, satisfaction and personal fulfilment. This is an alternative lifestyle that is achievable in contemporary care homes and exists alongside the possibility of living as the institutionalized product of staff work, the mere recipient of care. Older people consider that '*Living a life with care*' is a positive biographical equilibrium where the individual continues to (re)shape their personal biography during the final chapter of their life.

Implications for theory development

The understandings of care home life that have emerged through this study resonate with, and challenge, different theoretical perspectives across many disciplines including gerontology, environmental gerontology, environmental psychology, nursing, housing studies, social policy, sociology and social ecology. There are various possible contributions that this study can make to these disciplines by adding to existing bodies of literature and participating in professional and academic debate.

Older peoples' aspiration to live in care homes

The participants needed the care provided in the care home setting yet they did not want that care to take over their life experience. In those situations where the older person's life revolved around the routines of care, their biological functioning was maintained but they felt that they were no longer living in its fullest sense. This is akin to what has been described as social death where the individual continues to function biologically but little more than this. Social death has long been defined as the cessation of the individual as an active agent in their own life and in other people's lives (Glaser and Strauss, 1965). Social death is linked to but not predicated upon bodily death and in Western Society social death is increasingly occurring before the biological death event (Mulkay and Ernst, 1991).

Reconceptualizing the status of the resident as a person who lives with care refocuses attention on maintaining and supporting older people as active agents who continue to determine their own life rather than merely living in care, receiving care. The model of residents living biographically active lives provides an alternative biography to that of older people as recipients of care, and this has implications for theory development across disciplines. This alternative biography emerges from the world view of those who live in care homes and this offers different possibilities for older people to live out the remainder of their life. One consequence of this model of care home living is that it requires rethinking of the status of a resident.

Tenant or recipient of care

There is much variation and ambiguity concerning older people's status as residents of UK care homes, i.e. they are either tenants living in a care home under usual tenancy conditions with the privileges of life in a private setting, or they are recipients of long-term care. The predominant model of care in England includes no direct rights of tenure for occupancy of a place whilst receiving care. For example, a person requiring in-patient care in a NHS Trust has rights to access and receive care and treatment (National Health Service Act, 1946; 1973; and DoH, 1993). The occupancy of the bed in a NHS Trust is a consequence of receiving care, and ownership of the bed is retained by the

Trust. This model has been extended to the care home sector – the older person moving into a home enters into a contractual arrangement focusing on the care needs of the individual and the ability of the home to meet the needs of the resident (Office of Fair Trading, 1998). Here, housing, board and care are integrated, and one consequence of this is the emphasis on provision of an optimum level of care to the detriment of other needs such as lifestyle and social inclusion. Kane (2001) in a discussion of long-term care policy in the U.S.A. has highlighted the importance of conceptually separating housing and board from care and services to facilitate transformation of assisted living environments. In the UK context this would require considerable policy development, however, such a distinction would be a step in a direction that enabled older people to live in long-term care environments where the person was put before the task of care.

Within a biographically active model of care home living an older person may be a member of the resident population, but they retain the potential to live their life in the way that they want to do, with the support, care and treatment that they require to address their physical, functional and mental health needs. They may be a member of a care home's resident population but this does not deprive them of their full citizenship of the wider society to which they belong, and the rights associated with that status. They are an individual who ***lives with care*** and not one that ***exists in care***. This distinction enables the individual to transcend the status of the '*cared-for*' person. Though the distinction is subtle, it makes a significant difference to the way that residents are viewed and the way that other people respond to them. In some situations these models of care and citizenship sit comfortably together, but there is the potential for practice and ethical tensions and dilemmas when the models conflict with each other.

Older people as active decision-makers

There are a myriad of decisions that need to be negotiated in daily life in care homes. The evidence points to the way that older people are not always central to decision making processes and staff can restrict or limit residents' choices (McCormack, 1998; Graneheim, Norberg, & Jansson, 2001). This has

the potential of diminishing the possibilities for individuals determining their own life as a resident. Being biographically active implies that older people are engaged with decisions that affect them and that they are instrumental in determining the shape of their life in a care home, as depicted in the discussion of resident-led strategies in chapter 6.

In a review of health and social care literature, Cook and Klein (2005) identified that the principle of involving older people in planning their care and the services available to them was much discussed, yet progress toward implementing this in practice has been slow. Research studies continue to highlight the need for staff to engage with older people in a way that enables them to influence care decisions (McCormack, 1998; Clark & Dyer, 1998; HAS 2000, 1998). The discussion of the narrative theme 'Being in control/losing control' highlighted the types and range of decisions that residents can make (see p.201), however in many situations they required support to make and act on their choices. There needs to be much more theoretical development about the way that residents and care staff negotiate the minutia of daily life with each other, and what makes an effective negotiation strategy in this context.

Within the practice literature on participation, the emphasis is on involving older people in decisions about care, which has a problem focused orientation. Being involved in decisions about living a life as a resident in a care home is concerned with much more than solving health and functional problems. It is concerned with making decisions about the way that the individual wants to live the remainder of their life. This is consistent with biographical approaches that are developing in practice contexts (e.g. Meyers, 1989; Clarke, Hanson & Ross, 2003) whereby processes of assessment and care planning are concerned not only with the problems that the individual faces, but also with determining the life goals that they desire to fulfil. McCormack (2004) suggests that biographical approaches have the potential to '*adapt the context of care in order to create a caring environment that nurtures individual personhood*' (p. 34).

Care homes as complex self-organising systems

This quotation from McCormack (2004) makes reference to the caring environment and its influence on the individual's experience of care. This statement reflects a body of literature that has sought to develop a sophisticated understanding of the milieu of care (see for example, Peace, Kellher and Willcocks, 1997; Stanley and Reed, 1999; Davies, 2000; NCHR&D Forum, 2006). This growing body of work is emphasising the importance of developing care homes as communities, which are dynamic social environments where residents can thrive. The understandings that have been developed through the retelling of the participants' stories point to the need for a sophisticated understanding of the individuals' construction of the context that they live within. The model of living a biographically active life in care homes highlights the constant interaction that is occurring throughout all aspects of the social system and the ever developing construction that residents experience of that system. Though this model runs the risk of under-representing the subtleties that exist within the care setting, it does highlight the need to examine the social world of a care home at the individual level as well as developing understanding of the complexities of the institution.

Further research

The model developed through this study is at an early stage of development and requires further elaboration. The study contributes to understanding the ways that older people live in care homes and offers an alternative biography for care home living that is acceptable and desirable to older people. From the work carried out so far, there are further questions that can be asked about living biographically active lives in care homes. For example, questions could be asked whether older people want others to know about every aspect of their private life with the aim of supporting them to live the life to which they aspire. This opens up the potential impact of making public what is private as an area worthy of further investigation. Questions could also be asked about the ways that care staff recognize and respond to resident-led strategies. This strand of inquiry could lead onto investigating the approaches that are appropriate and acceptable to older people. In the light of the current emphasis on developing the care home community, questions could be asked

about the ways that the self-organizing behaviours of residents and staff may be harnessed to develop care homes as the communities that residents want to live in. At this stage in development, the findings from this study offer a way of acknowledging older peoples' aspirations for living in care homes and rethinking the models that currently exist. Further examination of questions arising from this study would require the support of policy making and research granting bodies to commit funds to explore these subjects.

There is also the potential to develop each of the narrative themes outside the scope of this study. For example, in the discussion of the narrative theme 'Relating to others/putting up with others' (see p.203), attention was drawn to the importance of social relationships within the care home setting to older people, and the challenges residents face in developing and maintaining those relationships. Some of this analysis pointed to gaps in current knowledge, therefore articles were developed to explore some of these ideas. For example, in the paper 'The risk to enduring relationships following the move to a care home' (Cook, 2006; see off-print in back folder). This paper examines risk in the context of sustaining relationships with long-term friends and the possibility of developing new friendships following the move to a care home. The paper drew on the resident's narratives to highlight the value of long-term friendships to residents and the strategies that they adopt to maintain those relationships.

In Cook, Brown-Wilson and Forte (2006; see off-print in back folder) the impact of sensory impairment on social interaction in the care home setting is examined. This paper focuses on the difficulties that older people with sensory impairment have in developing and maintaining relationships with fellow residents. Through examining resident narratives a range of approaches are identified to develop practices that support these people to develop meaningful relationships. By continuing to examine each of the narrative themes, an understanding of the lives of older people living in care homes will continue to develop.

Implications for practice

The understandings of care home life generated through this inquiry clearly point to the value that older people attach to being able to live with care and being instrumental in shaping that life. They valued the features of their life where they had a life experience (continuing to experience pleasure, fulfil aspirations and engage in those things that are meaningful in the context of their own biography) rather than a care experience (where daily activities are focused on and revolve around the provision of care). This conclusion resonates with, and adds to, recent debates concerning the need to develop high quality gerontological care in the practice literature.

There has been much discussion in contemporary practice literature on knowing the older person and grounding care in this knowledge; supporting older people through the transitions of moving to and from care homes and the end of their life; enhancing quality of life and quality of care; involving older people in decision-making; and developing practice and care environments that are enabling and nurturing that allow the older person to thrive in later life. Though the findings from this study may have implications for different facets of each of these categories of literature, there are two key contributions that are discussed here: the importance of knowing the older person and utilizing this knowledge to inform practice; and developing negotiating practices within the care home environment that support residents in their efforts to shape a life for themselves within the care home community.

Knowing the older persons' need, expectations and aspirations

The findings indicate that a gap exists between residents' understanding of what they need to enable them to live the way that they want to in a care home, and of the staff who are influential in structuring the care home environment. This does not suggest that care staff do not attempt to identify and respond to the needs of residents. They do this, but the scope of their efforts is mainly limited to identifying need and problems, rather than identifying and creating different possibilities for residents to live their life in a meaningful way in a care setting. These findings point to at least two areas of

practice that continue to require attention. First, the current emphasis on professional, technical knowledge as the key evidence underpinning practice should be balanced with a broader understanding and acceptance of knowledge of the person. Secondly, there ought to be wide-spread use of practices within the care home sector that optimizes access to and utilization of knowledge of the person to identify residents' needs, determine daily life and plan care.

Knowledge underpinning practice: Throughout the previous decade there has been growing concern about the appropriateness, fittingness and relevance of interventions, care and services that are solely derived from complex, technical professional knowledge. Such interventions, care and services may address need that has been identified by professionals, however this may not reflect need as defined by the service user, nor may it achieve the outcomes that they desire. For example, a grounded theory study discussed in Clarke and Heyman (1998) explored the views and concerns of individuals who were caring for their partners living with dementia. They concluded that partner-carers do not emphasize the technical knowledge of dementia pathology, but specific biographical knowledge of the impact of this long term illness on their life and that of their partner. The carers were particularly concerned about the loss of their partner's self-identity and the changes in their relationship with that person.

These authors argued that these different forms of knowledge exist within care situations, and these are a powerful influence on the way that service providers and service users perceive need and construct care. In the case that has been described, carers may place great emphasis on their need to sustain the relationship with their partner, who has dementia. This may cause them to identify ways to modify their living arrangements in order to accommodate changing needs as dementia progresses. Although the relationship will change, this strategy may enable them to continue to live in the family home, and maintain their daily interaction with each other. In contrast, professionals may focus on the hazards within the home environment. In this case the emphasis is on optimising safety and identifying

ways to minimise risk, such as moving the person with dementia to a protective environment that provides continuous supervision. From the professional perspective, relocating from the family home to a care home may be viewed as an appropriate care strategy. The way care is constructed from both of these perspectives can be justified, but the outcome for the individuals concerned will differ.

Nolan (2000), drawing on the work of Liaschenko and Fisher (1999) in the USA, has argued that the way care is constructed for older people emerges from an amalgam of different forms of knowledge. He argues that case knowledge (biomedical and disembodied knowledge of a particular condition), patient knowledge (case knowledge in context), and person knowledge (understanding of a biographical life) are all present in care practice. However, contemporary health care gives inordinate emphasis to professionally derived knowledge (which equates to case and patient knowledge) at the expense of knowledge of the person (Trinder 2000). This increases the potential failure of care to fulfil the desires of the older person, or meet their perceived needs.

Care staff need to draw on case and patient knowledge but not at the expense of knowledge of the person. In the context of a care home, this is particularly important because older people do not want care to take over their life experience. Older people, their families and friends are not empty vessels; they have much expertise to bring to this life experience and should be as instrumental as care staff in shaping that experience. Accessing the knowledge base of residents, however, is not straightforward. Even when considerable efforts are made by care staff to elicit the views of service users and other significant people, these people may be reluctant or unable to express their opinions.

Older people do need encouragement and support to participate in discussions concerning their need, priorities and expectations. The findings presented in chapters 5, 6 and 7 highlight the way that residents can express their views and discuss their concerns. They spoke of the strategies that they

developed to enable them to do the things that they want to do and what they had achieved. They also indicated that their efforts were not always recognised or supported. This poses a challenge to develop practice that recognises the contribution that older people can continue to make in the final phase of their life and to support them to make that contribution.

Approaches to eliciting person knowledge: The participants were frail and some had difficulty in articulating their views, yet they were able to tell stories about their life. This didn't just happen. These people needed to know that what they had to say was important and valuable in the context of the research process, and they needed constant reaffirmation of this. Communication strategies had to be developed, such as pausing to enable the participant to 'find' the words to express their opinions and summary processes that reflected what the person had said to facilitate continuity in the discussion when they had experienced a 'senior moment', a momentary lapse in concentration. These approaches to communicating with older people are not unique to this study; they are reflective of strategies that exist within practice. Recent literature suggests that effective communication with older people can be facilitated through a range of communication strategies such as eliciting information over time, consistent staff assignment, using photo cues and personal objects to encourage discussion (see Davies,2001b;Tester et al, 2004; Wells, 2005).

Whilst communication strategies enable staff to identify residents' needs and problems, there is growing evidence that these approaches can be used effectively within a biographical framework in practice to elicit knowledge of the person. McCormack (2004), in a review of person-centredness in gerontological nursing, argued that biographical approaches are used to collect stories as part of the assessment process. However, their utility is in understanding the older person's context and their aspirations. Using knowledge in this way provides the basis to integrate the older person's past, present and future experiences. Wells (2005) also points to the ethical value of biographical approaches as a philosophy underpinning care that drives

care staff to understand what matters from the perspective of the older person.

There are a range of biographical approaches to care including reminiscence, life-plans, life-story, life-review and life-diaries (Meyers,1989; Goldsmith, 1996; Mills, 1997; Heliker, 1999; Ford and McCormack, 1999; Kenyon, Clark and Vries, 2001; Clarke, Hanson and Ross, 2003; McCormack, 2004). These approaches enable care staff to develop a rich picture of the older person and an understanding of their perspective. By developing a shared understanding of what the person wants to do in life there is the opportunity for reflection on what has been, and the possibility of forming life-goals for their current and future life. In the context of the model of older people living with care, person knowledge can be made available through biographical approaches to inform decisions about care and lifestyle choices, thus optimizing the possibility that the life that the older person lives reflects their need and priorities.

Developing negotiating practices within care homes

Living a life with care means different things to different people. In each of the narrative themes older people have expectations of what they want to realize. As a consequence of frailty, illness and disability they are highly reliant on other people to support them to achieve this. Consequently they need to negotiate their care and lifestyle choices with care staff, family and friends (as discussed in chapters 6, 7, 8). This involves engagement with different types of decisions within the context of a care home, ranging from macro-organisational decisions to those that concern micro-level decisions about care and lifestyle choices.

Davies and Brown-Wilsons' (2006) review of the literature concerning decision making in the context of care homes led them to recommend the involvement of all the stakeholders within the care home community in decision-making processes. In this way the different perspectives of the various communities within this environment will inform decisions. The importance of residents contributing to decisions about their care and lifestyle, as well as those that affect the running of the care home is captured throughout chapter 5.

Informing decisions, however, is very different to influencing outcomes. A shift in decision-making power from care and management staff to the wider stakeholder community is necessary for this to happen. In recognition of this, these authors recommend the use of the decision-type typology that was developed by Rowles and High (2003) through an ethnographic study. Davies and Brown-Wilson suggest that this typology provides a framework for stakeholders to examine the different ways that they can be involved in decisions and the degree of influence that they can exert over these processes.

An integral element determining stakeholder's involvement in decision making processes, however, is their ability to negotiate the complex issues of context, environment and relationship and their communication competence to do this. According to McCormack (1998) it is these negotiations that are central to decisions that influence what takes place in the long-term care of older people. The findings presented in this thesis indicated that negotiation for older people is problematic in the context of care home life. The stories discussed in the earlier chapters provide evidence that residents are involved in decision-making processes within care homes, however their influence over outcomes is variable. The high level of communication competence that is required for older people to negotiate each dimension of care home life represented by the narrative themes with care staff, family and friends may be limited. This suggests that further research addressing negotiation processes is required to enable this aspect of practice to develop.

One possibility for this is through the development of specialised tools that can be adopted in practice to examine negotiation processes as well providing a framework for the development of the competence of those involved in decision-making processes. There are a limited number of tools that have been developed to examine processes of negotiation and the accompanying issues of autonomy and independence. The Power as Knowing Participation in Change Tool (PKPCT) is one such tool, but its development has mainly been through Ph.D. work, and it has not been extended significantly beyond this (Morris 1991). In addition, the PKPCT examines negotiation only from the

older person's perspective, and while these evaluations are important, it is some way off incorporating the activities of staff, family and friends.

Understanding the complexities of negotiations that take place between people within care homes will add to an understanding of the care home as a self-adapting system. It is within the negotiations between person, place and relationships that self-adaptive behaviours exist. Little is known about these negotiations, so research in this area has the potential to develop practice at the interface between the older person and their social world, as well as at the level of the care home community. The outcomes of this type of research could feed into the development of existing National Minimal Standards of care and in this way the provision and expectation of care may be enhanced in ways that reflect the views and concerns of older people.

Reflecting on the research journey – implications for research

Reflections on the research process

Older people living in care homes have, by and large, moved there because they are in need of a degree of care and support, or would anticipate this need arising in the future. As such they may be considered to be a 'vulnerable population', given that they may have health problems. Yet this should not prevent them from taking part in research. Health needs vary considerably and these problems do not necessarily impact on decision-making capacity. It should not, therefore, be assumed that residents are not competent to make their own decisions about participation in research or able to make a full contribution to the research process. Involving vulnerable, frail people in research, however, requires careful consideration of the method adopted in the study to ensure that participation is achievable.

Involving vulnerable, frail older people in this research did require thought, preparation, time and resources to ensure that they were provided with the opportunity to participate and express their views. Being sensitive and

responsive to the needs of different participants began with the first contact with them. For instance, those with sensory impairment(s) required assistance with hearing aids to enable them to take part in a conversation about the study, or provision of an audio-recording of the project information to assist them to recall the details of that conversation.

Being flexible with the participants and adapting to their needs was required at every stage of the study. It was anticipated that maintaining on-going dialogue with the participants for the entire research period may have been compromised by health problems (see p.53 & 60). Though this was anticipated, the reality of undertaking a series of interviews with people whose health fluctuated constantly was more difficult than expected. Interviews were cancelled and rescheduled, and they were brought to an abrupt halt when the participant suddenly felt unwell and unable to continue. These circumstances reinforced the appropriateness of the research design, which allowed for change as the participant's situations altered.

The participants had different communication abilities, so it was necessary to be flexible in the way that data was collected. Some participants were able to express their views clearly and coherently with little additional support. Others had significant communication problems. Edna, for example, suffered from expressive dysphasia, so a strategy of waiting or pausing whilst she searched for the words to describe her experience was negotiated with her at the commencement of the study. In contrast, what Gloria said was virtually inaudible at times as a consequence of advanced Parkinson's disease. Often her voice diminished as the interview progressed. To address this, notes were made immediately after the interview to supplement the transcription. These were checked with her as a way of confirming that they were an accurate reflection of what she had said. Practical issues such as these needed to be recognized and addressed in order to support the older people to take part in the study, a level of support that should not be underestimated in studies that seek to involve frail older people.

The series of interviews created a framework for dialogue to evolve between the researcher and the participants (see chapter 4, p.100: Developing a dialogue), and in the study this was viewed as a precondition for a *'coming'* together of the world views of the researcher and the researched. The feedback and discussion that took place during the interviews provided a way of developing the interpretation as the inquiry progressed, ensuring that the interpretation presented in chapters 5 - 8 represented the reality of living in a care home that was experienced by the older people who participated in the study. Though dialogue was integral to the inquiry as a way of addressing the issue of representativeness, it is acknowledged that this was limited to the sequence of interviews at the stage of data collection and throughout the naïve and structural interpretation. Ideally, dialogue would have continued throughout the study, but this was not possible as every participant had died before the research was completed. This is a dilemma of working with frail older people, but should not deter researchers from seeking innovative ways to verify that the interpretations arising from their work are trustworthy and a believable representation of experiences of the participants (Koch, 1996; Denscombe, 1998).

The importance of commencing the interview sequence with a life history interview was reinforced every time I reflected on my initial encounters with the participants and read their transcripts. When they spoke they told graphic stories of their life that enabled me to see beyond the older person who was frail and now living in a care home. This first interview provided the basis for the development of a relationship with each of the participants that I had not anticipated. At the end of this interview, they asked many questions about me and my personal life. At first I was quite concerned about how I should respond as this had the potential to influence neutrality within the research. If I decided to respond as the objective researcher who shared little of myself this had the potential to limit what they might have told in subsequent interviews. Alternatively a stilted response may have been construed by the participants as being rude. By responding to their questions and telling about my life I sensed that a mutual sharing had taken place between the researcher and researched. This often set the scene for subsequent interviews where the

older person established a time of discussion prior to the commencement of the interview in the way that people who know each other take time to discuss ordinary occurrences with someone that they felt comfortable with.

Throughout the interview sequence the participants required encouragement to tell stories of their life in the care home. Whilst the act itself closely resembled the way that they conversed with other people, they frequently stated that they "*had nothing interesting* (or of interest) *to say*". They needed reassurance that I was interested in listening to what they had to say, about events that they considered to be ordinary and their everyday occurrences. It was at this point that the value of building up a relationship with the participants was important. With encouragement they moved beyond brief superficial descriptions of the happenings in their daily life to tell of the experiences that had often been kept private. Though the value of narration as a way of enabling older people to articulate their views of their experiences has been reported in the literature (see p.52-56), the appropriateness of this form of data collection was reaffirmed time and again throughout the study.

Striving to listen to residents

The slim emphasis on the voice of older care home residents is notable in research which purports to represent them. If researchers carry out research in which they wish to privilege the voices of older people, in other words try and ensure that the views and experiences of older research participants take precedent over the views of academic researchers, then this has more than ideological implications - these aims must be translated into project management, design and methodology. The evidence from this study indicates that narrative methods provide a vehicle for frail older people to tell of their experiences and engage in a process that moves beyond the public stories of what they think that researchers want to hear to tell of their private inner world and their intimate experiences of living in a care home. The participants needed encouragement and support to do this, as discussed in the previous section, which points to the important role that researchers play in recognising the individual, social and organisational barriers frail older people face in participating in research and in working to overcome those

barriers.

Privileging the voice of older people requires more than good will, it demands considerable thought and planning. Data collection may be more time consuming and problematic and the use of innovative methodology will be required. The value of sustained data collection strategies, such as the sequence of narrative interviews that was adopted for this study, cannot be underestimated. Older people, particularly those who are frail and live in care homes, need time to build trust in their relationship with the researcher. Many older people have experienced situations where they have been invited to express their views only to find that they were not heard or their opinions were not valued. It takes time within the research encounter to address these barriers to participation and it is the researcher's responsibility to rise to these challenges and develop research that is sensitive to the needs of frail older people and actively facilitates access to their perspective.

Summary

This thesis provides a unique insight into the day-to-day experiences of a sample of older people who are living in care homes in North-East England. The method was innovative as it enabled the participants to tell stories over a period of four to six months of the life they had established in the care home that revealed their very personal, intimate experiences. These captured both the enjoyable and satisfying moments as well as those that were unpleasant and unfulfilling. Much has been learned about what matters to residents, and the overriding conclusion that can be drawn from these stories is that these older people were trying to live as active biographical agents who were instrumental in shaping their own life. They were able to do this to a greater or lesser extent and the conceptual model of biographical living that has been developed in this thesis provides a framework to depict the complex interactions that shape an individual's experience in this environment. An inherent feature of this model is recognition that residents are active agents

throughout their life in care homes, and this contributes to the growing body of literature that has pointed to this possibility.

Whilst this interpretation of care home life makes no claim to fully represent the experiences of older people who live in care homes at the turn of millennium, the understanding of care home life that has developed through this study does offer an alternative biography for living in care homes that is not only possible but achievable. This is a biography of frail older people living with care and experiencing lives that are meaningful, have a sense of purpose and are enjoyable. This image provides a vision for long-term care for older people that is grounded in their views and aspirations.

As this journey into the world of residents draws to a close, a new journey is just beginning for me. I have learned so much from the people I have met along the way and this has stimulated my curiosity to find out more of what exists further along the path that they have pointed me to. I now know that there are different possibilities for older people living in care homes - older people want to live with care. With this knowledge new challenges surface that will require commitment from care staff, service providers and policy makers to realize this vision for the many older people who live hidden away within the care home communities that exist within our societal communities.

I started off on my journey from a vantage point that led me to believe that there was much that I would be able to see if I moved beyond the horizons that had so long restricted my vision. I now see that the understandings that I have developed along the path that I have so far followed have formed the present that will be tomorrow's past. Understandings of care home life will continue to evolve and it is important that this is not limited to one particular vantage point. Older people can be active participants in shaping the present as well as the future for others who follow their journey across the entrance to a care home.

As this thesis draws to a close I bid farewell to the people I met along my journey. They are no longer with us, yet their stories live on beyond them.

These stories are available for others to see the world in which residents live within a care home and to understand how older people want to live their life in order that possibilities for living may become a future reality.

References

Abel-Smith, B. (1964) *The hospitals 1880-1948*. London: Heinemann.

Agar, M. & Hobbs, J.R. (1982) Interpreting discourse: coherence and the analysis of ethnographic interviews. *Geriatric nursing*, 7 pp. 83-84.

Age Concern (2004) Older people in the United Kingdom. Some basic facts 2004. http://www.ageconcern.org.uk/AgeConcern/media/factcard2004.pdf; accessed June 2005.

Agich, G.J. (1993) *Autonomy and long-term care.* Oxford University Press, Oxford.

Allen, I.; Hogg, D. & Peace, S. (1992) *Elder people: choice, participation and satisfaction*. London: Policy Studies Institute.

Anderson, R.; Issel, L.M. & McDaniel, R.R. (2003) Nursing homes as complex adaptive systems: relationship between management practice and resident outcomes. *Nursing Research,* 52(1) pp.12-21.

Apitzsch, U. (2000) *Biographical policy evaluation.* Introductory plenary: Biographical methods and professional practice. International Sociological Association RC 38 Biography and Society Conference, School of Health and Social Welfare, The Open University, London. 19th October 2000

Apitzsch, U. & Inowlocki, L. (2000) Biographical analysis A German school? in Chamberlayne, P.; Bornat, J. & Wengraf, T. *The turn to biographical methods in social science*. London / New York.: Routledge p. 53 – 70.

Arber, S. & Ginn, J. (1991) *Gender and later life: A sociological analysis of resources and constraints.* London: Sage.

Argyle, C.; Bright, L. & Clarke, A. (2000) *The choice is yours? An account of the pressures faced by older people looking for care homes.* London: Counsel and Care.

Armstron-Esther, C. A.; Brown, K. D. & McAfee, F. G. (1994) Elderly patients: still clean and sitting quietly. *Journal of Advanced Nursing,* 19(2), pp. 264-71.

Audit Commission (1996) *Balancing the care equation; Progress with community care.* London: HMSO.

Audit Commission (1997) *The coming of age: Improving care services for older people*. London: HMSO.

Bajekal, M. (2002) *Health survey for England 2000. Care homes and their residents.* London: The Stationary Office.

Barba, B.E. (2002) Nursing home environments. *Journal of Gerontological Nursing,*28(3), pp. 5-6.

Barrs, J. & Thomese, F. (1994) Communes of elderly people: between independence and colonization. *Journal of Aging Studies*, 8(4) pp. 341-356.

Barton, R. (1959) *Institutional neurosis*. Bristol: John Wright.

Bebbington, A.; Darton, R. & Netten, A. (2001) *Care homes for older people, vol. 2 Admissions, needs and outcomes.* Canterbury: PSSRU.

Belanger, T. (2003) Bibliography defined. Bibliographic Society of America. http://enwikipedia.org/wiki/bibliography. Accessed on 4.12.2006.

Benner, P. (ed) (1994) *Interpretive phenomenology : embodiment, caring, and ethics in health and illness.* London , Thousand Oaks, Calif. : Sage Publications.

Bergland, A. & Kirkevold, M. (2001) Thriving - a useful theoretical perspective to capture the experience of well-being among frail elderly in nursing homes? *Journal of Advanced Nursing,* 36(3), pp.426-432.

Bernard, H. R. (1988) *Research methods in cultural anthropology.* San Diego: Sage Publications.

Berdnt,J. (2004) When death comes in a nursing home: A ritual to say good-bye. *Generations,* 28(2), pp. 53-54.

Biedenham, P.J. & Normoyle, J. B. (1991) Elderly community residents reactions to the nursing home: an analysis of nursing home related beliefs. *Gerontologist,*31(1), pp. 107-115.

Biever, J. L.; Gardner, G. T. & Bobele, M. (1999) Social construction and narrative family practice. In Franklin, C. & Jordan, C. (eds) *Family practice – brief systems methods for social workers.* Brooks Cole.

Biggs, S.; Bernard, M.; Kingston, P. & Nettleton, H. (2000) Lifestyles of belief: narrative and culture in a retirement community. *Ageing and Society.* 20(6) pp.649 – 672.

Bland, R.; Bland, R.; Cheetham, J.; Lapsley, I. & Llewellyn, S. (1992) *Residential care for elderly people: Their costs and quality.* Edinburgh: HMSO.

Blendin. K. & Riordan. J. (1998) A moving story. *Health Service Journal,* 22nd Jan, pp. 30 – 31.

Bond, J. (1993) Living arrangements of elderly people. in, Bond, J.; Coleman, P. &. Peace,S. (eds) *Ageing in Society: An introduction to social gerontology.* 2nd edition, London: Sage. pp. 161-180.

Booth, T. (1993) Obstacles to the development of user centred services. in Johnson, J. & Slater, R. (eds) *Ageing and later life.* London: Sage, pp. 160-167.

Bornat, J.; Dimmock, B.; Jones, D. & Peace, S. (1998) Care in the new family: Changing contexts for traditional obligations. in Silva, E. & Smart, C. (eds) *The new family.* Sage: London. pp. 115-128.

Bowers B. J., Fibich B., Jacobson N. (2001). Care-as-service, care-as-relating, care-as-comfort: understanding nursing home residents' definitions of quality. *The Gerontologist,* 41 (4), pp. 539-45.

Bowie, P. & Mountain, G. (1993) Using direct observation to record the behaviour of long-stay patients with dementia. *International Journal of Geriatric Psychiatry.* 8, pp. 857-864.

Bowlby, J. (1951) *Maternal care and mental health.* Geneva World Health Organisation: London HMSO; New York Columbia University Press.

Bridges, J. (2006) Working to help residents maintain identity. in NCHR&D Forum (ed) *My Home Life: quality of life in care homes. A review of the evidence.* Help the Aged:London, pp. 59-74.

Brown, C. & Thompson, K. (1994) A quality life: searching for quality of life in residential service for elderly people. *Australian Journal on Ageing,* 13(3), pp.131-133.

Bruner, J. (1995) The autobiographical process. *Sociology.* 43(2/3) p.177-179.

Bryant, L. L.; Corbett, K. K. & Kutner, J. S. (2001) In their own words: a model of healthy aging. *Social Science and Medicine.* 53(7), p p.927-941.

Burholt, V. (1998) Pathways into residential care: service use, help and health prior to admission. *Health Care in Later Life,* 3(10), pp.15-33.

Burnard, P. (1991) A method of analysis of interview transcripts in qualitative research. *Nurse Education Today,* 11, pp.461 – 466.

Byrne, D. (1998) *Complexity theory and the social sciences : an introduction.* London : Routledge.

Byrne, M. (2001) Hermeneutic as a methodology for textual analysis. *AORN* 73(5), pp.968-970.

Campbell, S. M.; Jagger, C. & Clarke M. (1993) Residential care for elderly people: a decade of change. *British Medical Journal,* 306, pp. 827-830.

Cantley, C.; Smith, M.; Clarke, C. & Stanley, D. (1999) *An independent supported living house for people with early onset dementia: evaluation of a dementia care initiative project.* Newcastle: Dementia North.

Caring Times, January (2002) Government must change direction, says RNHA http://www.careinfo.org/cgi-bin/news.pl?item=1011805425&archive=on; accessed on 5th June 2003.

Centre for Policy on Ageing (1984) *Home life: A code of practice for residential care.* Report of a working group sponsored and convened by the Centre for Policy on Ageing under the chairmanship of Lady Averbury. London: HMSO.

Centre for Policy on Ageing (1996) *A better home life.* London: Centre for Policy on Ageing.

Centre for Policy on Ageing, Department of Health (1998/99) *Benchmark Standards for Residential and Nursing Homes. Consultation Process.* London: Centre for Policy on Ageing.

Chalfont, G. (2005) *Architecture, Nature and Care: the importance of connection to nature with reference to older people and dementia.* School of Architecture, University of Sheffield.

Chamberlayne, P.; Bornat, J. & Wengraf, T. (ed) (2000) *The turn to biographical methods in social science. Comparative issues and examples.* London and New York: Routledge.

Chenitz, W.C. (1983) Entry into a nursing home as status passage: a theory to guide nursing practice. *Geriatric Nursing,* 4, pp.92–97.

Clarke, A (2000) Using biography to enhance the nursing care of older people. *British Journal of Nursing,* 9, pp.429-433.

Clarke, A.; Hanson, E.J.; & Ross, H. (2003) Seeing the person behind the patient: enhancing the care of older people using a biographical approach. *Journal of Clinical Nursing.* 12,pp.697-706.

Clarke, C. L. & Heyman, B. (1998) Risk management for people with dementia. in Heyman, B. (ed) *Risk, health and Health Care.* London: Arnold, pp. 228-241.

Clark, H. & Dyer, S. (1998) Equipped for Going Home from Hospital. *Health Care in Later Life,* 3(1), pp. 35-45.

Clark, P. & Bowling, A. (1990) Quality of everyday life in long stay institutions for the elderly: An observational study of long stay hospital and nursing home care. *Social Science and Medicine,* 30(11), pp. 1201-1210.

Cohen, M. Z.; Kahn, D. L. & Steeves, R. H. (2000) *Hermeneutic phenomenological research: A practical guide for nurse researchers. Methods in nursing research.* Sage Publications Inc.

Collins English Dictionary (1999). *Collins English Dictionary,* 4th edition. Harper Collins Publishers.

Collopy, B.J. (1988) Autonomy in long-term care: some crucial distinctions. *The Gerontologist.* 28(suppl), pp. 10-17.

Collopy, B.; Boyle, P. & Jennings, B. (1991) New directions in nursing home ethics. in Daniels, N. (ed) *Duty to treat or right to refuse?* Hastings Centre Report (Special supplement), 21(2) p.1-15.

Cook, G. (2003) *Creating personal life space in a care home: the experiences of older residents.* Unsettling the ordinary – changing ideas about ageing, British Society of Gerontology Conference. Newcastle upon Tyne. 4 – 6 Sept 2003.

Cook, G (2006) The risk to enduring relationships following the move to a care home,' *International Journal of Older People Nursing,*1(3), pp 182-185.

Cook, G; Brown-Wilson, C & Forte, D. (2006) The impact of sensory impairment on social interaction between residents in care homes, *International Journal of Older People Nursing*, 1, (4), pp 216 – 224.

Cook, G. and Klein, B. (2005) Involvement of older people in care, service and policy planning: A literature scan. *International Journal of Older People Nursing,* 14(3a), pp. 43 -47.

Cook, G.; Reed, J.; Sullivan, A. & Burridge, C. (2001) *Moving in and moving on: Transition of older people between and within care homes.* Centre for Care of Older People. University of Northumbria at Newcastle. ISBN: 861350996.

Cookman, C. A. (1996) Older people and attachment to things, places, pets and ideas. *Image: Journal of Nursing Scholarship,* 28(3), pp.227-231.

Cooper, C. (1974) The house as a symbol of the self. in Lang, M. J.; Burnette, C.; Moleski, W. & Vachon, D. (eds) *Designing for human behavior: Architecture and the Behavioral Sciences.* Stroudsburg, Dowden, Hutchinson and Ross Inc.

Cordon, A. & Wright, K. (1993) Going into a home: where can an elderly person choose? In Champion, T. (ed) *Population Matters.* London: Paul Chapman Publishing. pp. 119-135.

Counsel and Care (1991*) Not such private places : a study of privacy and the lack of privacy for residents in private and voluntary residential and nursing homes in Greater London.* London: Counsel and Care.

Counsel and Care (2000*) The choice is yours: An account of pressures faced by older people looking for care homes.* London: Counsel and Care.

Crossby, M. (2000) *Introducing narrative psychology. Self and the construction of many.* Routledge publishers.

Croucher, K.; Pleace, N. & Bevan, M. (2003) *Living at Hartrigg Oaks: Residents views of the UK's first continuing care retirement community.* Joseph Rowntree Foundation, York Publishing Services Ltd.

Cuba, L. & Hummon, D. M. (1993) A place to call home. Identification with dwelling, community and region. *Sociological Quarterly,* 34(1), pp. 111-131.

Davies, S. (2001a) *Relatives experiences of nursing home entry: a constructivist inquiry.* Unpublished PhD thesis, University of Sheffield.

Davies, S (2001b) The care needs of older people and family caregivers in continuing care settings. in Nolan, M.R.; Davies, S. & Grant, G. (eds) *Working with older people and their families.* Buckingham, Philadelphia: Open University Press. p. 75-98.

Davies, S. (2003) Creating community: the basis for caring partnerships in nursing homes. in Nolan, M.; Grant, G.; Keady, J., and Lundh, U. (eds.) *Partnerships in Family Care.* Buckinghamshire, Philadelphia: Open University Press, pp 218- 237.

Davies, S. & Nolan, M. (2003) 'Making the best of things': relatives' experiences of decision about care-home entry. *Ageing and Society,* 23, pp. 429-450.

Davies, S. & Heath, H (2006) Quality of care. in NCHR&D Forum (ed) *My Home Life: quality of life in care homes. A review of the evidence.* Help the Aged: London, pp. 35-44.

Davies, S. & Brown-Wilson, C. (2006) Creating a sense of community. in NCHR&D Forum (ed) *My Home Life: quality of life in care homes. A review of the evidence.* Help the Aged: London, pp. 76-99.

Day, P.; Klein, R. & Redmayne, S. (1996) *Why regulate? Regulating residential care for elderly people.* Bristol: Policy Press.

Dean, M. (2003) *Growing older in the 21st century: An ESRC Research Programme on Extending Quality of Life.* Economic and Social Research Council.

Dellasega, C. & Mastrian, K. (1995) The process and consequences of institutionalizing an elder. *Western Journal of Nursing Research* 17, pp.123–140.

Denscombe, M. (1998) *The good research guide.* Buckingham: Open University Press.

Denzin, N. K. (1989) *Interpretative biography.* London: Sage.

Department of Health and Social Service Inspectorate (1989) *Homes are for living in: a model of evaluating quality of care provided and quality of life experienced in residential care homes for elderly people.* London: HMSO.

Department of Health (1989) *Caring for people: Community Care in the next decade and beyond.* London: HMSO.

Department of Health (1990) *The NHS and Community Care Act.* London: HMSO

Department of Health (1993) *The Patient's Charter.* London: H.M.S.O.

Department of Health (1998) *Modernizing Social Services: Promoting independence, improving protection, raising standards.* (Command Paper 4169).London: HMSO.

Department of Health (2000) *The NHS Plan – A Plan for Investment. A Plan for Reform.* (Command Paper 4818-1) London: HMSO.

Department of Health (2001a) *Care Homes for Older people, National Minimum Standards.* London: HMSO

Department of Health (2001b) *Care Homes Regulations.* HMSO, London.

Department of Health (2001c) *National Service Framework for Older People.* London: Department of Health.

Department of Health (2001d) Research Governance Framework for Health and Social Care. London: Department of Health

Department of Health (2004a) Integrating community equipment services; Community equipment and care homes. http://www.icesdoh.org/downloads/ICES%20Equipment%20and%20Care%20Homes%2012%20October%202004%20-%20Main%20document.doc; accessed on 18.8.06.

Department of Health (2004) Integrating community equipment services; Community equipment and care homes. Appendix F, http://www.icesdoh.org/downloads/ICES%20Equipment%20and%20Care%20Homes%20Appendix%20F%20flowcharts%2012%20October%202004.doc; accessed on 18.8.06.

Depres, C. (1991) The meaning of home: literature review and directions for future research and theoretical development. *The Journal of Planning Research,* 8, pp. 96-115.

Dewing, J (2002) From ritual to relationship: a person-centred approach to consent in qualitative research with older people who have a dementia. *Dementia,* 1(2), pp.157-171.

Diamond, T. (1992) *Making Gray Gold: Narratives of nursing home care.* Chicago: University of Chicago Press.

Dielelmann, N. (2001) Narrative pedagogy: Heideggerian hermeneutical analyses of lived experiences of students, teachers and clinicians. *AMS,* 23(3), pp. 53-72.

Edgar, I. R. (1986) *An anthropological analysis of Pepper Harrow therapeutic community with particular reference to the use of myth, ritual and symbol.* University of Durham.

Egger M, Davey Smith G, Altman DG (2001) *Systematic Reviews in Health Care.* London: British Medical Journal Books.

Ekstrom, M. (1994) Elderly people's experiences of housing renewal and housing relocation: social theories and contextual analysis in explanations of emotional experiences. *Housing Studies,* 9(3), pp. 369-391.

Eley, R. and Middleton, L. (1983) Square pegs , round holes. The appropriateness of providing care for older people in residential settings. *Health Trends,* 15(2), pp.68-70.

E-Map (2001) *General nursing perspectives in the care of older people.* E-Map Healthcare Ltd.

Eyers, I. A. (2003) *Meeting the needs of older people? A comparative study of care home staff in England and Germany.* Unpublished PhD thesis Department of Sociology, School of Human Sciences, University of Surrey.

Faden, R. & German, P. (1994) Quality of life: considerations in geriatrics. *Clinics in Geriatric medicine,*10(3), pp. 541-550.

Farquhar, M. (1995) Elderly people's definitions of quality of life. *Social Science and Medicine,* 4 1(10), pp. 1439-1446.

Fiveash, B. (1998) The experience of nursing home life. I*nternational Journal of Nursing Practice*, 4, pp.166-174.

Flick, U. (1998) *An introduction to qualitative research.* Sage Publications: London.

Flick, U. (2000) Episodic interviewing. in Bauer, M. W. & Gaskell, G. *Qualitative researching with text, image and sound. A practical handbook.* Sage publications, pp. 75-92.

Flower, J. (1993) Creating a forum. *Community Care.* 45(9), pp. 20-21.

Ford, P.; Blackburn, S.; Heath, H.; McCormack, B. & Phair, L. (1997) *RCN Assessment Tool for nursing older people.* London, Royal College of Nursing Publishers.

Ford, P.; Heath, H.; McCormack, B. & Phair, L. (1998) *What a difference a nurse makes: An RCN report on the benefits of expert nursing to the clinical outcomes in the continuing care of older people.* London, Royal College of Nursing Publishers.

Ford, P. & McCormack, B. (1999) Keeping the person in the centre of nursing. *Nursing Standard,* 14(46), pp. 40-44.

Friedmann N. L., Montgomery R. J., Rice C. & Farrell L. (1999) Family involvement in the nursing home. *Western Journal of Nursing Research,* 21(4), pp. 549-567.

Gadamer, H-G. (1975) *Truth and method.* Seabury: New York.

Gadamer, H-G. (1976) *Philosophical hermeneutics.* (Linge, D. ed) London: University of California Press.

Gadamer, H-G. (1989) *Truth and method.* 2nd revised edition. Revised and translated by Weinsheimer, J. & Marshall, D. New York: Continuum Publishing.

Gelwicks, L. E. (1970) Home range and use of space by an aging population. in Pastalan, L. & Carson, D. (eds) (1970) *Spatial behaviour of older people.* The University of Michigan - Wayne State University. Ann Arbor Michigan, pp. 148-161.

Geyer, R. (2000) *Exploring European social policy.* Polity Press.

Glaser, B. G. (1998) *Doing grounded theory: ideas and discussions.* Mill Valley, CA: Sociology Press.

Glaser, B. G. & Strauss, A. L. (1965) *Awareness of dying.* Aldine : New York.

Goffman, E. (1961) *Asylums. Essays on the social situation of mental patients and other inmates.* London: Penguin Books.

Golant, S. M. (1998) Changing an older person's shelter and care setting: a model to explain personal and environmental outcomes. in Scheidt, R. J. & Windley, P. G. (eds) *Environment and ageing territory.* A focus on housing. Westport CT:Greenwood Press, pp.33-60.

Goldsmith M (1996) *Hearing the voices of people with dementia: opportunities and obstacles.* London: Jessica Kingsley.

Goodman, N. (1980) Twisted tales: or story, study and symphony. *Critical Inquiry,* 7, pp.103-119.

Goodman, C. & Woolley, R.J. (2004) Older people in care homes and the primary care nursing contribution: a review of relevant literature. *Primary Health Care Research and development,* 5, pp.211-218.

Graneheim, U.H.; Norberg, A. & Jansson, L. (2001) Interaction relating to privacy, identity, autonomy and security. An observational study focusing on a woman with dementia and 'behavioural disturbances', and on her care providers. *Journal of Advanced Nursing,* 36(2), pp.256-265.

Grau, L. & Wellin, E. (1992) The organisational cultures of Nursing homes: Influences on responses to external regulatory controls. *Qualitative Health Research,* 2 (1), pp. 42-60.

Grau, L.; Chandler, B. & Saunders, C. (1995) Nursing home resident' perceptions of the quality of their care. *Journal of Psychosocial Nursing and Mental Health Services*, l33(5), pp. 34-43.

Greenhalgh, T. & Hurwitz, B. (1999) Why study narrative? *British Medical Journal*, 318, pp.48-50.

Griffiths Report (1998) *Community Care, Agenda for Action*. London: HMSO.

Groger, L. (1995) A nursing home can be home. *Journal of Aging Studies,* 9(2), pp.137-153.

Grondin, J. forward by Hans Georg Gadamer translated by Weinsheimer, J. (1994) *An introduction to philosophical hermeneutics.* New Haven; London: Yale University Press.

Guba, E. G. & Lincoln, Y. S. (1989) *Fourth generation evaluation.* Newbury Park CA: Sage Publications.

Gubrium, J. F. (1995) *Individual agency, the ordinary and postmodern life.* Milton Keynes: School of Health and Social Welfare, Centre for Ageing and Biographical Studies, The Open University Press.

Gubrium, J. F. & Holstein, J. A. (eds) (2003) *Ways of Aging.* Blackwell Publishing.

Gurney, C. & Means, R. (1993) The meaning of home in later life. in Arber, S. & Evandrou, M. (eds) *Ageing, independence and the life course.* London: Jessica Kingsley.

Guthiel, I. A (1991) Intimacy in nursing home friendships. *Journal of Gerontological Social Work,*17(1/2), pp. 59-73.

Haas, B. K. (1999) Clarification and integration of similar quality of life concepts. *Image: Journal of Nursing Scholarship,* 31(3), pp. 215-220.

Hanson J, Kellaher L, Rowlands M, Percival J, Marcoux J and Zako R (2003) Profiling the housing stock for older people from domesticity to caring. http://www.bartlett.ucl.ac.uk/research/space/housingfutures/2-EQUAL/UCL_EQUAL.pdf; accessed 6.6.06.

Harper-Ice, G. (2002) Daily life in a nursing home. Has it changed in 25 years. *Journal of Aging Studies,* 1694, pp. 345-359.

Hart, C. (1998) *Doing a literature review: Releasing the social science research imagination.* London: Sage Publications.
Health Advisory Service 2000 (1998) *Not because they are old ... - An independent inquiry into the care of older people on acute wards in general hospitals.* London: The Health Advisory Service 2000.

Health Survey for England 2000 (2002) *The health of older people.* London Stationary Office in conjunction with National Centre for Social Research, Department of Epidemiology and Public Health, University College London.

Heidegger, M. (1962) *Being and Time.* English translation of Sein und Zeit by Macquarrie, J. & Robinson, E. New York: Harper and Row.

Heliker, D. (1999) Transformation of story to practice: an innovative approach to long-term care. *Issues in Mental Health Nursing,* 20(6), pp. 513- 525.

Hepworth, M (2000) *The stories of ageing.* Buckinghamshire, Philadelphia: Open University Press:

Heywood, F.; Oldman, C. & Means, R. (2002) *Housing and home in later life.* Buckinghamshire, Philadelphia: Open University Press.

Higgins, J. (1989) Defining community care: realities and myths. *Social Policy and Administration*, 23(1), pp. 3-16.

Higgs, P. & Victor, C. R. (1993) Institutional care and the lifecourse. in Arber, S & Evandrou, M. (eds) *Ageing, independence and the lifecourse.* London: Jessica Kingsley. pp.104-130.

Higham, P. (1994) *Individualising residential care for older people.* Conference paper presented at BSG Annual Conference, University of London, September.

Holm, S. (2000) The hermeneutics of medicine and the phenomenology of health - steps towards a philosophy of medical practice. *Journal of Medical Ethics,* 26(1), p p. 61-62.

Homer, S. (1998) *Fredric Jameson: Marxism, hermeneutics, postmodernism.* Oxford: Policy Press.

Hoskins, J. (1998) *Biographical objects: How things tell the stories of people's lives.* New York and London: Routledge.

Hooyman, N. (1983) Social support networks in services to elderly people. in *Social support networks: Informal helping in the human services.* Whittaker, J. & Garbarino, J. (eds) Aldine, New York. pp.133-163.

House for Life Report, 1999-2000 (2001) *House for Life, Newcastle*, compiled by Douglas, B. Newcastle: A Better Life in Later Life/ Newcastle Healthy City Project.

Hubbard, G.; Tester, S. & Downs, M. (2004) Meaningful social interactions between older people in institutional care settings. *Ageing and Society*, 23(1), pp. 99-114.

Husserl, E. (1962) *Ideas: General introduction to pure phenomenology.* New York: .Collier Macmillan.

Hyden, L. (1997) Illness and narrative. *Sociology and Health and illness,* 19(1), pp. 48-69.

Illich, I. (1971) *Celebrations of awareness.* New York: Calder and Boyers.

Iwasiw, C.; Goldenberg, D.; MacMaster, E.; McCutcheon, S. & Bol, N. (1996) Residents' perspectives of their first two weeks in a long term care facility. *Journal of Clinical Nursing,* 5, pp. 381-388.

Iwasiw, C.; Goldenberg, D.; Bol, N. & MacMaster, E. (2003) Resident and family perspectives: The first year in a long-term care facility. *Journal of Gerontological Nursing*, 29(1,) pp.45-54.

Jerrome, D. (1992). *Good company: an anthropological study of old people in groups.* Edinburgh: Edinburgh University Press.

Jerrome, D. & Wenger, C. (1999) Stability and change in late-life friendships. *Ageing and Society,* 19, pp. 661-676.

Jewell, S. (1996) Elderly patients' participation in discharge decision making. *British Journal of Nursing*, 5(17), pp.1065-1071.

Johnson, N. (2004) Making decisions and being involved. *Nursing and Residential Care,* 6(9), pp.443 - 444.

Johnson, R. A.; Schwiebert, V. B. & Rosenmann, P. A .(1994) Factors influencing nursing home placement decisions. *Clinical Nursing Research*, 3(3), pp. 269-281.

Johnson, M. & Hoyes, L. (1996) *Moving forward....To a single registered home: A paper prepared for the Joseph Rowntree Foundation.* Bristol, School for Policy Studies.

Jones, H. (1979) *The residential community: A setting for social work.* London: Routledge and Kegan Paul.

Jovchelovitch, S. & Bauer, M.W. (2000). Narrative interviewing. in Bauer, M.W. & Gaskell, G. (eds.), *Qualitative researching with text, image and sound* London: Sage, pp. 57-74.

Kaakinen, J. (1995) Talking among elderly nursing home residents. *Topics in Language Disorder,* 15, p p. 36-46.

Kahn, D.L. (1990) *Living in a nursing home: Experiences of suffering and meaning in old age.* Bell & Howell Company, UMI Dissertation Services, MI.

Kahn, D. L. (1999) Making the best of it: Adapting to the ambivalence of a nursing home environment. *Qualitative Health Research,* 9(1), pp. 119-132.

Kane, R. A.; Caplan, A. L.; Urv-Wong, E. K.; Freeman, I. C.; Aroskar, M. A. and Finch, M. (1997) Everyday matters in the lives of nursing home residents: wish for and perception of choice and control. *Journal of the American Geriatrics Society,* 45(9), pp. 1086-93.

Kane, R. A. (2001) Long-term care and a good quality of life: Bringing them closer together. *The Gerontologist,* 41(3), pp.293-305.

Kane, R. A.; Kling, K; Bershadsky, B and Kane, R. (2003) Quality of life measures for nursing home residents. *The Journals of geronotology: Series A: Biological Sciences and Medical Sciences,* 58A (3), p.240-249.

Katz, J. S. & Peace, S.M. (2003) *End of life in care homes: a palliative care approach.* Oxford University Press

Kellaher, L. A. (2000) *A choice well made: Mutuality as a governing principle in residential care.* London: Centre for Policy on Ageing/Methodist homes.

Kellett, U. M. (1999) Transition in care: Family carers' experience of nursing home placement. *Journal of Advanced Nursing,* 29, pp. 1474-1481.

Kenyon, G; Clark, P & Vries, B. (2001) *Narrative gerontology: Theory, research and practice.* Springer Publishing Company.

Klein, B. & Cook, A (1998) Concepts of quality in residential care and nursing homes: UK and German perspectives. *Health Care in later Life,* 3(1), pp.48-57.

Koch, T. (1994) Establishing rigour in qualitative research: the decision trail. *Journal of Advanced Nursing,* 19 pp. 976-986.

Koch, T. (1996) Implementation of a hermeneutic inquiry in nursing: philosophy, rigour and representation. *Journal of Advanced Nursing,* 24(1) pp. 174-184.

Koch, T. (1999) An interpretive research process: revisiting phenomenological and hermeneutical approaches. *Nurse Researcher,* 6(3), pp. 20-35.

Kovach, S. & Robinson, J. (1996) The roommate relationship for the elderly nursing home resident. *Journal of Social and Personal Relationships,* 13(4), pp. 627-634.

Kvale, S. (1996) *An introduction to qualitative research interviewing.* London: Sage.

Laing, W. (2002) *Healthcare Market Review 2001-2.* London: Laing and Buisson.

Laing and Buisson (2003) Long term care. http://www.laingbuisson.co.uk/StatisticsInformation/LongTermCare/tabid/71/Default.aspx Accessed 14.12.06

Laing and Buisson (2004). *Laings' healthcare market review 2004-2005, incorporating the Fitzhugh directory of independent healthcare financial information.* 17th Ed. Laing and Buisson. London.

Lawton, M. & Simon, B. (1968) The ecology of social relationships in housing for the elderly. *Gerontologist,* 8, pp.108-115.

Lawton, M. (1970) Ecology and aging. in Pastalan, L. & Carson, D. (eds) (1970) *Spatial behaviour of older people.* The University of Michigan - Wayne State University. Ann Arbor Michigan, pp. 40-67.

Lee, D.T.F. (1997) Residential care placement: perceptions among elderly Chinese people in Hong Kong. *Journal of Advanced Nursing,* 26, pp. 602-607.

Lee, D.T.F. (2002) A review of older people's experiences with residential care placement. *Journal of Advanced Nursing,* 37(1), pp.19-27.

Lee, G. & Ishii-Kuntz, M. (1987) Social interaction, loneliness, and emotional well-being among the elderly. *Research on Aging,* 9(4), pp. 459-482.

Lees, J. (2004) *A culture of inquiry; research evidence and the therapeutic community.* London: Jessica-Kingsley.

Lee-Treweek, G. (1996) Emotion work, order and emotional power in care assistant work. in James, V. & Gabe, J. (eds) *Health and the sociology of emotions.* Oxford: Blackwell publishers. p. 115-132.

Lee-Treweek, G. (1997) Women resistance and care: An ethnographic study of nursing auxiliary work. *Work, Employment and Society,* 11(1), pp.47-63.

Leon, A; Pastalan, L. & Carson, D. (eds) (1970) *Spatial behaviour of older people.* The University of Michigan - Wayne State University: Ann Arbor

Michigan.

Liaschenko, J. & Fisher, A. (1999) Theorizing the knowledge that nurses use in the conduct of their work. *Scholarly Inquiry for Nursing Practice,* 13(1), pp. 29-41.

Lincoln,Y, S and Guba, F. G (1985) *Naturalistic inquiry.* Beverly Hills: Sage

Lloyd, L. & Cameron, A. (2005) Significant life events: developing knowledge for care at the end of
life in old age. *Journal of Integrated Care,* 13 (3), pp. 4-39.

MacIntyre, A. (1980) Epistomological crises, dramatic narrative, and the philosophy of science. in Gutting, G. (ed.) *Paradigms and revolutions.* Indiana: University of Notre Dame Press.

MacDonald, A; Craig, T. & Warner, L. (1985) The development of a short observation method for the study of the activity and contacts of old people in residential settings. *Psychological Medicine.* 5. pp. 167-172.

McAuley, W. J.; Travis, S. S. & Safewright, M. P. (1997) Personal accounts of the nursing home search and selection process. *Qualitative Health Research,* 7(2), pp. 236-254.

McAuley, M. & Usita, P. (1998) A conceptual model for the mobility patterns of nursing home admissions. *The Gerontologist,* 38(6), pp. 726-734.

McCloud Clark, J. & Latter, S. (1992) Working together. *Nursing Times,* 86(48), pp.28-31.

McCormack, B. (1998) *An Exploration of the Theoretical Framework Underpinning the Autonomy of Older People in Hospital and its Relationship to Professional Nursing Practice.* Unpublished D.Phil. Thesis, Department of Educational Studies, University of Oxford.

McCormack, B. (2004) Person centeredness in gerontological nursing: an overview of the literature. *International Journal of Older People Nursing,*13(3a), pp.31-38.

McKee, K.; Harrison, G. & Lee, K. (1999) Activity, friendships and wellbeing in residential settings for older people. *Aging and Mental Health,* 3(2), pp. 143-152.

McKee, K.; Downs, M.; Gilhooly, M.; Gilhooly, K.; Tester, S. & Wilson, F. (2005) Frailty, identity and the quality of later life. in Walker, A. (ed), *Understanding quality of life in older age.* Buckinghamshire, Philadelphia: Open University Press, pp. 117-129.

Maddox, G. L. (2003) Making a house a home. *The Gerontologist,* 43, pp.931-934.

Marcoux, J. S. (2001) The 'Casser Maison' ritual. *Journal of Material Culture,* 6(2), pp. 213-235.

Marshall, V. (1999) Reasoning with case studies: Issues of an aging workforce. *Journal of Aging Studies,* 13(4), pp. 377 – 389.

Mairis, M. (1994) Concept Clarification in Professional Practice - Dignity. *Journal of Advanced Nursing,*.19, pp. 947 - 953.

Maguire, S. J. (1991) *Gadamer's hermeneutics: criticism and community.* PhD dissertation, Queens University, Kingston, Ontario, Canada.

Marcoux, J. (2001) The 'Casser Maison' ritual. *Journal of Material Culture,* 6(2), pp. 213-235.

Mattiasson A. & Andersson L. (1997) Quality of nursing home care assessed by competent nursing home patients. *Journal of Advanced Nursing,* 26(6), pp. 1117-24.

Means, R. & Smith, R. (1985) *The development of welfare services for older people.* London: Croom Helm.

Merleau-Ponty, M. (1968) *The visible and the invisible.* Northwestern University Press: Evanston, IL.

Meyer, J.; Spilsbury, K. & Prieto, J. (1999) Comparison of findings from a single case study in relation to those from a systematic review of action research. *Nurse Researcher.* Winter, 7(2), pp.37-59.

Meyers, D. T. (1989) *Self, society and personal choice.* Columbia University Press, New York.

Mezirow, J. (1990) *Fostering critical reflection in adulthood; a guide to transformative and emancipatory learning.* San Francisco: Jossey-Bass Publishers.

Mischler, E. G. (1992) Work, identity and narrative: Am artist-craftman's story. in Rosenwald, G. C. & Ochberg, R. L. (eds) *Storied lives. The cultural politics of self-understanding,* New Haven: Yale University Press, pp. 21-40.

Mischler, E. G. (1995) Models of narrative analysis: A typology. *Journal of Narrative and Life History,* 5(2), pp. 87-123.

Millard, P. (1999) *Nursing home placements for older people in England and Wales. A national audit 1995-1998.* Department of Geriatric Medicine, London, St. George's Medical School.

Miller, E.J. & Gwynne, G.V. (1972) *A life apart. A pilot study of residential institutions for the physically handicapped and the young chronic sick.* Tavistock Publications, J.B. Lippincott Company.

Mills,M. (1997) Narrative, identity and dementia: a study of emotion and narrative in older people with dementia. *Ageing and Society,* 17(6), pp. 673-698.

Mor, V.; Branco, K.; Fleishman, J.; Hawes, C.; Phillips, C.; Morris, J. & Fries, B. (1995) The structure of social engagement among nursing home residents. *Journal of Gerontology*, 50B(1), pp.1-8.

Morris, D. L. (1991) *An Exploration of Elders' Perceptions of Power and Well Being.* Case Western University (Health Sciences). PhD dissertation.

Mulkay, M. & Ernst, J. (1991) *The changing profile of social death.* Archives europeennes de sociologie, XXX11, p.172-196.

Muller-Vollmer, K. (ed) (1985) *The hermeneutics reader.* Padstow: T. J. Press Ltd.

Mulrow, C. J (1994) Systematic Reviews: Rationale for systematic reviews. *British Medical Journal*, pp.597-599.

Nay, R. (1993) *Benevolent oppression: Lived experience of nursing home life.* Unpublished Doctoral Thesis. the University of new South Wales, Australia.

Nay, R. (1995) Nursing home residents' perception of relocation. *Journal of Clinical Nursing,* 4(5), pp.319-325.

NCHR&D Forum (ed) (2006) *My Home Life: quality of life in care homes. A review of the evidence.* Help the Aged: London.

Neill, J. (1989) *Assessing people for residential care: A practical guide.* National Institute of Social Work Research Unit, London.

Netten, A.; Bebbington, A.; Darton, R. & Forder, J. (2001). *Care homes for older people. Volume 1. Facilities, Residents and Costs.* Canterbury. PSSRU.

Netten, A.; Darton, R. & Williams, J. (2003). Nursing home closures: effects on capacity and reasons for closure. *Age & Ageing.* 32 (3), pp.332-337.

Nolan, M. R. (1997) *Health and social care: what the future holds for nursing.* Keynote address at Third Royal College of Nursing Older Person European Conference and Exhibition, Harrogate. Cited in Working with older people and their families: Key issues in policy and practice. Nolan, M.; Davies, S. & Grant,G. (eds) Buckinghamshire, Philadelphia: Open University Press, p.17.

Nolan, M. & Dellasega, C. (1999) It's not the same as him being at home': creating caring partnerships following nursing home placement. *Journal of Clinical Nursing,* 8(6), pp. 723-30.

Nolan, M. R. & Grant, G. (1992) Mid-ranging theory building and the nursing theory-practice gap: a respite care case study. *Journal of Advanced Nursing,* 17(2), pp. 217-223.

Nolan, M. R.; Grant, G. & Nolan, J. (1995) Busy doing nothing; activity and interaction levels amongst differing populations of elderly patients. *Journal of Advanced Nursing,* 22, pp.528-538.

Nolan. M. R.; Walker, G.; Nolan, J.; Williams, S.; Poland, F.; Curran, M. & Kent, B. C. (1996) Entry to care: Positive choice or fait accompli? Developing a more proactive nursing response to the needs of older people and their carers. *Journal of Advanced Nursing*, 24(2), pp.265-274.

Nolan, M. R. (2000) Towards person centred care for older people. in Warnes, A.; Warren, L. & Nolan, M. (eds) *Care services for later life.* London and Philadephia: Jessica Kingsley Publishers, pp. 54-74.

Nolan, M. R. & Davies, S. (2000) The health and care of older people in care homes: the way forward or recreating the past? *Quality in Ageing - Policy, Practice and Research*, 1(2), pp.4-6.

Nolan, M. R.; Davies, S. & Grant, G. (2001) Integrating perspectives. in *Working with older people and their families: Key issues in policy and practice.* Nolan, M; Davies, S and Grant,G (eds) Buckinghamshire, Philadelphia: Open University Press, p p.4-18.

Nolan M, Davies S, Brown J, Keady J and Nolan J (2002) *Longitudinal Study of the Effectiveness of Educational Preparation to Meet the Needs of Older People and Carers: The AGEIN Project.* English National Board, London.

Nolan, M; Davies, S; Brown, J; Keady, J. and Nolan J. (2004) Beyond 'person-centered' care: a new vision for gerontological nursing. International Journal of Older People Nursing, 13(3a), pp.45-53.

Nuffield Foundation (1947) *Old people. Report of a survey committee on the problems of ageing and the care of old people, under the chairmanship of B. Seebohm Rowntree.* London: Oxford University Press.

Office of Fair Trading (1998) *Older people as consumers in care homes. A report by the Office of Fair Trading.* London: Office of Fair Trading.

Office of Fair Trading (2005). *Care homes for older people in the UK. A market study.* London: Office of Fair Trading.

O'Kell, S. (1995) *Care Standards in Residential Care Sector.* YPS for the Joseph Rowntree Foundation, York Publishing Services Ltd.

Oldman, C. & Quilgars, D. (1999) The last resort? Revisiting ideas about older people's living arrangements. *Ageing and Society,*19, pp. 363-384.

Outhwaite, W. (1987) *New philosophies of social science: Realism, hermeneutics and critical theory.* London: Macmillan Education.

Palmer, R. E. (1969) *Hermeneutics: Interpretation theory in Schleiermacher, Dilthey, Heidegger, and Gadamer.* Northwestern University: Press.

Parker, C.; Barnes, S.; McKee, K.; Morgan, K.; Torrington, J. & Tregenza, P. (2004) Quality of life and building design in residential and nursing homes for older people. *Ageing and Society*, 24: 941-962.

Parmalee, P. & Lawton, M. P. (1990) The design of special environments for the aged. in Birren, J. & Schaie, K. (eds) *Handbook of the psychology of aging.* San Diego, CA: Academic Press, pp. 464-488.

Paternity, D. A. (2003) Claiming identity in a nursing home. in Gubrium, J. F. & Holstein, J. A. *Ways of aging.* Blackwell Publishing, pp.58-74.

Patterson, B. J. (1995) The process of social support: adjusting to life in a nursing home. *Journal of Advanced Nursing,* 21, pp. 682-689.

Peace, S. (1993) The Living environments of older women. in Bernard, M. & Meade, K. (eds) *Women come of age.* London: Edward Arnold.

Peace, S. M.; Kellaher, L. & Willcocks, D. (1997) *Re-evaluating residential care.* Buckinghamshire, Philadelphia: Open University Press.

Peace, S. and Holland, C. (2001) Homely residential care: A contradiction in terms. *Journal of Social Policy,* 30(3), pp.393- 410.

Peace, S. M. & Reynolds, J. (2004) Managing different expectations of place and space: Part two. *Nursing and Residential Care,* 6(9), pp. 452-454.

Pearson A (2004) Balancing the evidence: incorporating the synthesis of qualitative data into systematic reviews. *JBI Reports,* 2: pp.45-64.

Personal Social Services Research Unit (PSSRU) (2001) *Residential and nursing home care of elderly people.* Cantebury: PSSRU, University of Kent, Cantebury.

Petersen, E. (1995) *Trivsel og livskvalitei, krise og samfundsudvikling - en antologi* (Thriving and Quality of Life, crisis and the development of society). Psykologisk Institut, Aarhus Universitet, Aarhus, Denmark.

Petersen, E. (1997) *Livskvalitet, resignation og overlevelse. En prospektiv undersogelse av 292 kraeftbehandlede kvinder - beskrevet un fra Trivselsteorien* (Quality of life, resignation and survival. A prospective investigation of 292 women treated for cancer - Described in terms of the theory of thriving. Psykologisk Institut. Aarhus, Universitet, Aarhus, Denmark

Plummer, K. (1997) *Telling sexual stories. Power, change and social worlds.* Routledge.

Pontin, D. (1999) Primary nursing: a mode of care or philosophy of nursing? *Journal of Advanced Nursing,*29(3), pp. 584-591.

Porter, E. (1989) The qualitative-quantitative dualism. *IMAGE the Journal of Nursing Scholarship,* 21(2), pp. 99.

Priest, H. M. (2000) The use of narrative in the study of caring: A critique. *Nursing Times Research*, 5(4), pp. 245-252.

Quality of Life Partnership (2006) *Improving the quality of life of older people in Newcastle.* Newcastle, Quality of Life Partnership.
Rappaport, J. (1977) *Community psychology: Values, research and action.* New York: Holt, Rinehart and Winston.

Raynes, N. (1998) Involving residents in quality specification. *Ageing and Society,* 18, pp. 65-78.

Redfern S (1993) In pursuit of quality of nursing care. *Journal of Clinical Nursing*, 2, pp. 141-148.

Reed, J. (1988) *Gerontological nursing research – future directions.* Paper given to the Agenet/ Royal College of Nursing gerontological nursing research seminar, Regents College, London December.

Reed, J. (2006) Quality of life. in NCHR&D Forum (ed) *My Home Life: quality of life in care homes. A review of the evidence.* Help the Aged: London, pp. 26-34.

Reed, J.; Procter, S. & Murray, S. (1996) A sampling strategy for qualitative research. *Nurse Researcher.* 3(4), pp.52-68.

Reed, J. & Payton, V. (1996) *Working to create continuity: older people managing the move to the care home setting.* Report 76. Centre for health services Research, University of Newcastle upon Tyne. ISBN 1-870399-69-2

Reed, J. & Payton, V. (1997) Understanding the dynamics of life in care homes for older people; implications for de-institutionalising practice. *Health and Social Care in the Community*, 5(4), pp. 261-268.

Reed, J.; Cook, G. & Stanley, D. (1999) Promoting partnership with older people through quality assurance systems: issues arising in care homes. *Nursing Times Research,* 4(5), pp. 353-363.

Reed, J.; Cook, G.; Sullivan, A. & Burridge, C. (2003a) Making a move – residents in care homes' experiences of re-location. *Ageing and Society,* 23, pp. 225-241.

Reed, J.; Klein, B.; Cook, G. & Stanley, D. (2003b) Quality improvement in German and UK care homes. *International Journal of Health Care Quality Assurance,* 16(5), pp. 248-256.

Reed, J.; Cook, G.; Childs, S. & Hall, A. (2003c) *'Getting old is not for cowards,' comfortable healthy ageing.* Joseph Rowntree Foundation, York Publishing Services Ltd.

Reed, J.; Cook, G.; Bolter, V. & Douglas, B. (2006) *Older people getting involved and getting things done.* Joseph Rowntree Foundation, York Publishing Services Ltd.

Reed, J.; Roskell Payton, V. & Bond, S. (1998) The importance of place for older people moving into care homes. *Social Science and Medicine,* 46(7), pp. 859-867.

Reed, J.; Stanley, D. & Clarke, C. (2004) *Health, well-being and older people.* Bristol: The Policy Press.

Reed, J; Cook, G and Cook, M (2004) Research governance issues in the care home sector. *Nursing Times Research,* 9(6), pp.430-439.

Reeder, F. (1988) Hermeneutics. in Sarter, B (ed.) *Paths to knowledge: Innovative Research methods for nursing.* National League for Nursing, New York, pp. 193-238.

Retsinas, J. (1991) Triggers to nursing home placement. *Geriatric Nursing* 12, pp. 235–236.

Retsinas, J. & Garrity, P. (1985) Nursing home friendships. *The Gerontologist,* 25(4), pp. 376-381.

Ricoeur, P. (1976) *Interpretation theory. Discourse and surplus of meaning.* Forth, Worth, Texas: USA: Christian University Press.

Ricoeur, P. (1991) *From text to action. Essays in hermeneutics.* Evanston, IL, USA: Northwestern University Press.

Rihani, S. (2002) *Complex systems theory and development practice : understanding non-linear realities.* London : Zed Books.

Robb, B. (ed) (1967) *Sans everything: A case to answer.* London: Nelson.

Roberts, B. (2002) *Biographical research*. Buckinghamshire, Philadelphia: Open University Press.

Rosswurm, M. A. (1983) Relocation and the elderly. *Journal of Gerontological Nursing,* 9, pp. 632–637.

Rowles, G. D. (1978) *Prisoners of space? Exploring the geographical experience of older people.* Boulder CO, Westview.

Rowles, G. D. (1981) The surveillance zone as a meaningful space for the aged. *Gerontologist*, 21(3), pp. 304-311.

Rowles, G.D. & High, D.M. (2003) Family involvement in nursing Home Facilities. A decision making perspective. in Stafford, P. (ed) *Gray areas:ethnographic encounters with nursing home cultures*. Santa Fe. New Mexico. School of American Research.

Royal Commission on Long Term (1999) *With respect to old age - a report by the Royal Commission on Long Term Care*. London: HMSO.

Royal College of Physicians, Royal College of Nursing, British Geriatrics Society (2000) *The health and care of older people in care homes: a comprehensive interdisciplinary approach: a report of a joint working party.* London Royal College of Physicians.

Ruangjiratain, S. (1998) Understanding women's risk of HIV infection in Thailand through critical hermeneutics. *Advanced Nursing Science*, 21 (2), pp.42-51.

Ryan, A. & Scullion, H. F. (2000) Nursing home placement: an exploration of the experiences of family carers. *Journal of Advanced Nursing*, 32(5), pp. 1187-1195.

Sandberg, J.; Lundh, U. & Nolan, M. R. (2001) Placing a spouse in a care home: the importance of keeping. *Journal of Clinical Nursing*, 10, pp. 406-416.

Sandberg, J.; Nolan, M. R. & Lundh, U. (2002) The role of community staff in care home placement in Sweden. *Journal of Clinical Nursing*, 11, pp. 488-497.

Sandelowski, M. (1986) Problems of rigor in qualitative research. *Advances in Nursing Science,* 8(3), pp. 27-37.

Saunders, P. (1989) The meaning of home in contemporary English culture. *Housing Studies,* 4, pp. 177-192.

Savishinsky, J. S. (1991) The *Ends of Time: Life and Work in a Nursing Home.* New York: Bergin and Garvey.

Schon, D. (1983) *The reflective practitioner.* London: Temple Smith.

Schutze, F. (1977) Die Technik des narrativen interviews in Interaktionsfeldstudiendargestellt an einem Projekt zur Erforschung von kommunalen Machstrucktren. Unpublished manuscript, University of Bielfeld, Department of Sociology.

SCIE (2004) Research briefing 10: Terminal care in care homes. http://www.scie.org.uk/publications/briefings/briefing10/index.asp, accessed 18.8.06.

Seymour, J. & Clark, D. (2001) Palliative care and geriatric medicine: shared concerns, shared challenges. *Palliative Medicine*, 5(4), pp. 269-270.

Seymour, J. & Hanson, E. (2001) Palliative care and older people. in Nolan, M. R. ; Davies, S.; & Grant, G. (eds) *Working with older people and their families. Key issues in policy and practice*. Buckinghamshire, Philadelphia: Open University Press, pp. 99-119.

Shannon, R. A. (1998) The implementation of the key worker system. *Assignment*, 4(4), pp.19-28.

Shay, J. (1994) *Achilles in Vietnam: Combat trauma and the undoing of character*. New York: Atheneum.

Sidell, M. & Komaromy, C. (2003) Who dies in care homes for older people? Katz, J. S. & Peace, S. (eds) *End-of-life-care in Care Homes. A Palliative Care Approach*. Oxford, Oxford University Press, pp. 43-58.

Sixsmith, A. (1990) The meaning and experience of home in later life. in Bytheway, W. R. & Johnson, J. (eds) *Welfare and the ageing experience: A multidisciplinary analysis.* Aldershot: Averbury, pp. 172-192.

Sixsmith, A. J. & Sixsmith, J. A. (1991) Transitions in home experiences in later life. *The Journal of Architectural and Planning*, 8, pp. 181-191.

Silverman, D. (1993) *Interpreting qualitative data.* London, Sage.

Sklar, E.& Hartley, S. F. (1990) Close friends as survivors: Bereavement patterns in the hidden population. *Omega,* 21, pp. 103 – 112.

Slater R. (1995) *The psychology of growing old: looking forward*. Open University Press, Buckingham, Philadelphia.

Smith, B. (1999) Ethical and methodological benefits of using a reflexive journal in hermeneutic-phenomenologic research. *The Journal of Nursing Scholarship,* 31 (4), pp. 359 – 364.

Sommer, R. (1970) Small group ecology in institutions for the elderly. in Pastalan, L. & Carson, D. (eds) (1970) *Spatial behaviour of older people.* The University of Michigan - Wayne State University: Ann Arbor Michigan, pp.25-39.

Spradley, J. P. (1979) *The ethnographic interview.* New York: Holt, Rinehart,

Stafford, P. B. (2003) Homebodies: voices of place in a North American community. in Stafford, P. B. (ed.) *Gray Matters: Ethnographic Encounters with Nursing Home Culture,* School of American Research Press, Santa Fe, pp 121-152.

Stanley, D. & Reed, J. (1999) *Opening up care.* London: Arnold publishers.

Stea, D. (1970) Home range and use of space. in Pastalan, L. and Carson, D. (eds) (1970) *Spatial behaviour of older people.* The University of Michigan - Wayne State University: Ann Arbor Michigan, pp.138-147.

Steven, A. (1999) Named nursing: in whose best interest? *Journal of Advanced Nursing*, 29(2), pp. 341-347.

Strauss, A. & Corbin, J. (1998) *Basics of qualitative research. Techniques and procedures for developing grounded theory.* London: Sage publications.

Swann, J. (2004) Equipment for living: The value of assistive devices. *Nursing and Residential Care,* 7(2), pp. 74-77.

Swann, J. (2005) Making life easier: Improving access in care homes. *Nursing and Residential Care*, 7(1). Pp. 24-26.

Tesh, A. S.; McNutt, K.; Courts, N. F. & Barba, B. E. (2002) Characteristics of nursing homes: Adopting environmental transformations. *Journal of Gerontological Nursing*, 28(3), pp. 28-34.

Tester, S.; Downs, M. & Hubbard, G. (2000) *Exploring perceptions of quality of life of frail older people during and after their transition to institutional care.* ESRC Getting Older Programme.

Tester, S. Hubbard, G. Downs, M. MacDonald, C. & Murphy, J. (2004) What does quality of life mean for frail residents? *Nursing & Residential Care,* 6(2), pp. 89-92.

The Information Centre, Government Statistical Service (2006) *Community care statistics 2006, supported residents (adults) England. The Information Centre. http://www.ic.nhs.uk/pubs/ccs06suppres/ccsadultreport/file, accessed 13.12.06*

Thompson, J. B. (1981a) (editor and translator) *Paul Ricoeur. Hermeneutics and the human sciences.* Cambridge University Press

Thompson J.B (1981) (editor and translator) Critical hermeneutics: A study in the thought of Paul Ricoeur and Jurgen Habermas

Titchen, A. (2000) *Professional craft knowledge in patient-centered nursing and the facilitation of its development.* Doctoral Thesis, University of Oxford, Ashdale press oxford.

Titchen, A. (2001) Skilled companionship in professional practice. in Higgs, J. & Titchen, A. (eds) *Practice Knowledge and Expertise in the Health Professions.* Oxford: Butterworth Heinemann, pp. 69-79.

Tobin, S. S. & Lieberman, M. A. (1976) *Last Home for the Aged.* London: Jossey-Bass.

Townsend, P. (1962) *The last refuge.* London: Routledge and Kegan Paul.

Townsend, P. (1981) *The family and later life. Contemporary issues in Education.* Buckinghamshire, Philadelphia: Open University Press.

Traupmann, J.; Eckels, E. & Hatfield, E. (1992) Intimacy in older women's lives. *The Gerontologist*, 22(6), pp. 493-498.

Trinder, L. A. (2000) Critical appraisal of evidence-based practice. in Trinder, L. & Reynolds, S. (eds.) *Evidence-based practice: A critical appraisal.* Oxford: Blackwell Science, pp. 212-241.

Victor, C. (1992) Do we need institutional care? in Laczko, F. & Victor, C. (eds) *Social policy and elderly people*. Gower Aldershop, Hampshire, pp.259-275.

Voelkl, J. E.; Fires, B. E. & Galecki, A. T. (1995) Predictors of nursing home residents' participation in activity programs. *The Gerontologis,* 35(1), pp. 44-51.

Wahl, H. (2001) Environmental influences on ageing and behaviour. in Birren, J. E. & Schaie, K. W. (eds) *Handbook of the psychology of ageing.* (5th edition), New York: Academic Press, pp. 215-232.

Waldrop, M. M. (1992) *Complexity : the emerging science at the edge of order and chaos.* New York: Simon & Schuster.

Warnes, A. M. (1982) *Geographical perspectives on the elderly.* Wiley, Chichester.

Warnke, G. (1987) *Hermeneutics, tradition and reason.* Oxford: Polity Press.

Warren, N. (2002) Critical care family members' satisfaction with bereavement experiences. *Critical Care Nursing Quarterly*, August, 25(2), pp. 54-60.

Wellman, B. & Hall, A. (1986) Social networks and social support: implications for later life. in Marshall, V. (ed) *Later life: The psychology of aging*, Beverly Hills: Sage, pp.191-231.

Wells, D. (2005) Biographical and developmental approaches. in Heath, H. & Watson, R. (eds.) *Older people: assessment for health and social care* Glasgow: Age Concern.

Wenger, G. C. (1990) The special role of friends and neighbours. *Journal of Aging Studies,*.4(2), pp.149-169.

Whitler, J. M. (1996) Ethics of assisted autonomy in the nursing home: Types of assisting among long-term care nurses. *Nursing Ethics,* 3(3), pp.224-235.

Willcocks, D.; Peace, S. & Kellaher, L. (1987) *Private lives in public places*. London, New York: Tavistock Publications.

Williams, B. & Grant, G. (1998) Defining people-centredness: making the implicit explicit. *Health and Social Care in the Community,* 6(2), pp. 84-94.

Wilson, S. A. (1997) The transition to nursing home life: a comparison of planned and unplanned admissions. *Journal of Advanced Nursing,* 26 pp.864-871.

Wittenberg, R.; Comas-Herrera, A.; Pickard, L. & Hancock, R. (2004). *Future demand for long-term care in the UK. A summary of projections of long-term care finance for older people to 2051.* Joseph Rowntree Foundation, York Publishing Services Ltd.

Wolins, M. (1974) *Successful group care.* Chicago: Aldine publishing company..

WHOQoL Group (1998) The World Health Organisation Quality of Life Assessment (WHOQoL): development and general psychometric properties. *Social Science and Medicine*, 46, (12), pp.1569-1585.

Wright, F. (2000) *Capital offences: Variations in local authority treatment of older home owners entering residential care. A summary of some key research findings.* Age Concern. Institute of Gerontology. Kings College London.

Zimmerman, S.; Sloane, P.D.; Williams, C.S.; Reed, P.S.; Preisser, J.S.; Eckert, J.K.; Boustani, M. & Dobbs, D. (2005) Dementia care and quality of life in assisted living and nursing homes. *The Gerontologist,* Special Issue No.1, pp. 133-146.

Acts of Parliament

Care Standard Act (2000)
Data Protection Act (1998)
National Health Service Act (1946)
National Health Service Reorganisation Act (1973)
National Health Service and Community Care Act (1990)
The Registered Homes Act (1984)

Appendices

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Inserts in the back page pocket

Off print of Cook, G (2006) The risk to enduring relationships following the move to a care home,' *International Journal of Older People Nursing,*1(3), pp 182-185

Off print of Cook, G; Brown-Wilson, C & Forte, D.(2006) The impact of sensory impairment on social interaction between residents in care homes, *International Journal of Older People Nursing*, 1, (4), pp 216 - 224

Appendix one: Research Study information sheet

Title of Study- An exploration of the experiences of older people and the influences on their experience of communal living in a nursing care home.

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends, relatives and staff in the care home. Ask me if there is anything that is not clear or if you would like more information. Take time to decide if you wish to take part.

This study is being carried out by the Centre for Care of Older People, University of Northumbria at Newcastle. The research proposal has been reviewed by the Faculty of Health, Social Work and Education, University of Northumbria research degrees committee, Sunderland Health Authority research ethics committee and Newcastle and North Tyneside research ethics committee.

The study seeks to explore older people's experiences of living in communal living arrangements in nursing homes. The views of older people about the factors influencing their experiences will also be explored. There is much known about the ways older people select a nursing home to live in, how they experience the move to a nursing home and adapt to life in this new environment. Yet, there is little known about the views of older people about living in a care home where they negotiate their care and preferred living arrangements with other residents and care home staff.

I am particularly interested in the experiences and views of older people who live in this setting influencing the way other people practice and think about life in later years in a communal living setting. Therefore, I would like to listen to the stories of older people to obtain their accounts and their views of life as a resident in a nursing home.

Eight older people who are living in 4 different nursing homes will be invited to take part in a series of 8 interviews to tell their story. The interviews will take place throughout a period of 4 months. The length of each interview will be determined by the older person, however the interviews will usually last no longer than between 40 minutes and 1.5 hours. In addition, to the interviews with older people I would like to interview those who have influenced the older person's experience of communal living in the home. Therefore, interviews with others such as nursing, care staff and activities co-ordinators may be arranged.

I would like to tape record the interviews to enhance the accuracy of the outcomes of this study. All information which is collected during the course of this study will be kept in a secure place and all personal details will be removed so that you cannot be recognised from it. Following completion of

the study the tapes will be erased.

The findings from the research will be used to increase understanding of older people's experience of living in a nursing home community and enable the development of practice in this environment. Following completion of this study the participants will receive a summary of the findings. In addition the outcomes of this study will be reported in professional and academic literature, however, please be reassured that all results will be presented with identifying information removed.

If you have any concerns about any aspect of the way you have been approached or treated during the course of this study please contact either Professor Jan Reed or Professor David Stanley using the contact information given below.

It is up to you to decide whether or not to take part in this study. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. I must make clear that contributing to or withdrawing from the study will not affect the standard of care you receive in the home.

Thank you for reading this. More information about the study is available from:

Glenda Cook
Centre for Care of Older People,
Room H017
Coach Lane Campus East,
Northumbria University
Newcastle upon Tyne
NE7 7XA
Tel: 0191 2156117
e-mail: glenda.cook@unn.ac.uk

Contact information

Professor Jan Reed
Centre for Care of Older People,
Coach Lane Campus East,
Northumbria University
Newcastle upon Tyne
NE7 7XA
Tel: 0191 2156142

Professor David Stanley
Centre for Care of Older People,
Coach Lane Campus East,
Northumbria University
Newcastle upon Tyne
NE7 7XA
0191 2156261

Appendix two: Consent form

Title of Study- An exploration of the experiences of older people and the influences on their experience of communal living in a nursing care home.

In this study a researcher will be interviewing older people to explore their experiences of living in communal living arrangements in care homes and their views about the factors influencing their experiences. If you decide to be part of this study, this will involve taking apart in a series of interviews where you will be invited to tell your story. The series of interviews will take place over a period of 4 months and the length of each interview will be determined by you, however, the interviews will usually last no longer than between 40 minutes and 1.5 hours. The interviews will take place in the nursing home you live in.

All the information given in the interview will remain confidential and anonymous. No information will be disclosed to anyone outside the research team, and all results will be presented with identifying information removed. Consent to take part in the study can be withdrawn at any point if you wish.

I have had this study explained to me and I understand that I will be interviewed and all information will remain confidential. I also understand that I can withdraw my consent at any time.

Signed: _____

Date: _____

Appendix three: Local Research Committee Approval Letters

Sunderland NHS
Health Authority

Durham Road
Sunderland
SR3 4AF

Tel: 0191 565 6256
Fax: 0191 528 3455
Ext 45290

JO'C/WH/HMW/

19 February 2001

Ms G Cook
Senior Lecturer (Nursing Research)
University of Northumbria
Faculty of Health, Social Work & Education
Research Office, Room H009
Coach Lane Campus East
NEWCASTLE UPON TYNE NE7 7XA

Dear Ms Cook

An exploration of the experiences of older people and the influences on their experience of communal living in a nursing care home

Thank you for your recent letter enclosing the amended patient information sheet for the above study. The necessary changes have been made in line with the discussions at a recent Ethics Committee meeting.

I am now happy to grant approval to your study by Chairman's action. The decision will be ratified at the next meeting of the Ethics Committee.

May I take this opportunity to wish you success in your project. We look forward to receiving a progress report in due course.

Best wishes.

Yours sincerely

J. O'Connell

Dr J E O'Connell BSc MBChB FRCP
Chairman
Sunderland Local Research Ethics Committee

SUNDERLAND Health Authority

Chairman: Joe L. Mills OBE DL
Chief Executive: Roy McLachlan MA MBA MIHM Dip IHSM

INVESTOR IN PEOPLE

Newcastle and North Tyneside NHS
Health Authority

JOINT ETHICS COMMITTEE
Newcastle & North Tyneside Health Authority
University of Newcastle upon Tyne
University of Northumbria at Newcastle

Benfield Road
Newcastle
NE6 4PF

Your Ref:

31 January 2001

Ms G Cook
Senior Lecturer
Room H009
Nursing Research and Development Unit
Coach Lane Campus East
University of Northumbria at Newcastle
NEWCASTLE UPON TYNE NE7 7XA

Dear Ms Cook

An Exploration Of The Experiences Of Older People And The Influences On Their Experience Of Communal Living In A Nursing Care Home
(Min Ref: 2001/07)

Thank you for your letter of 26 January which addresses the issues identified by the Joint Ethics Committee when it considered your application in respect of this study.

In the light of your response I can now confirm the grant of ethical approval in respect of your research study application.

Yours sincerely

Mr W M Ross
Acting Chairman
Joint Ethics Committee

tel: (0191) 219.6009
fax: (0191) 219.6066

Appendix four: Diary notes recorded during Anne's first interview and Anne's interpretation file from interview 1

Interview ID – Anne

Interview 1 – 16th Feb 2001

Initial reflections on the interview

She has had a varied lifestyle and in her earlier years she enjoyed contact with others and interacting in a range of activities. Her description of her life was vivid and heavily laden with specific time markers and specific events. The most significant events appeared to occur in relation to her family. She is interested in other people, however her physical problems have had a great impact on her social relationships.

This lady had suffered enormously from different types of physical problems including arthritis, disc problems for which she had had surgery on 2 occasions, and latterly she had become partially sighted (she could only see the outline of shapes). These problems resulted in limitations on her social contact with others and the types of activities she was able to take part in.

She now has little social contact with others outside of he nursing home. Her family had either died or now her close family lived in New Zealand. Contact was maintained through weekly telephone discussion.

She spoke of the nursing home staff as friends and she was interested in them as people. She desired further contact with staff, not to address physical needs but to share personal events, discuss daily activities and so on. Her desire was balanced with the knowledge that she knew that the staff were busy and had many demands placed on them by other residents, therefore she did not push to gain further contact for what appeared to be seen as "passing the time" activities.

Issues:

- Deterioration in physical health
- The influence of personality on a residents views about their living arrangements
- Her need for social contact with the staff
- The major impediments she encountered in developing and maintaining relationships with other residents
- The impact of physical limitations on residents relationships with each other
- Influence of staff change on residents experience of care in the home

Story files:

1. Anxiety provoking spinal treatment
2. A manager's efforts to provide care
3. Change in work due to ill-health
4. A needed vacation with a sister
5. Mothers deteriorating health
6. Negative views of the care home her mother had lived in
7. Her sons relocation to New Zealand
8. Visiting her son and his family in New Zealand with her sister
9. Death of a beloved sister
10. Returning home alone
11. A turbulent journey to New Zealand
12. Deteriorating health and making decisions about long-term care
13. Choosing and moving to a care home
14. Living beside others in a care home
15. Catching up with her family when they visited from New Zealand
16. More bad news – facing permanent deterioration of her vision
17. Difficulties encountered in relating to other people in the care home
18. Organising activities in the home

19. Staff absences
20. Working in sales – a busy and exciting time
21. Living through the war – evacuation, anxiety and tragedy
22. The changing value of money
23. My sister the wonderful salesperson
24. A pension received following a life-time of work

Topic files: Reflections following transcription

1. Suffering from chronic ill-health
(During her adult years she experienced spinal problems that required surgery. Later in life she was diagnosed as having spinal arthritis – she made no mention of these conditions being related to each other. These conditions led to multiple problems the key ones that she repeatedly mentioned being pain and immobility)
"I was in and out of plaster and traction and what have you and then Mr 'T,' the surgeon decided yes we could do a spinal fusion (raised voice) so the um he took me in and I was in for nine months till I got made better."

"Then I took another attack of crippling arthritis which they diagnosed later as arthritis in the spine. The surgeon I saw said there was no way could another surgeon go in to the back again. They had taken part of my hip bone out to put in my spine and he said you will not find a surgeon who would do that - it is a question of learning to live with it. The pain was atrocious. I was in and out of hospital and then back home."

2. Negative view of care homes
(When her mother had temporarily moved to a care home this made a negative impression on her)
They put her in a home once. (long pause 6 seconds) It was a terrible place (her voice changed to a low tone) It was an old broken down big house in Jesmond. The garden wall was lying in the garden. Now when you opened the door the smell was atrocious. (pause 4 seconds) So they took us into a big long room with two rows of chairs facing each other with a space between them for the wheelchairs to go through. I never saw any wheel chairs in that home. And they just sat there facing each other. Nobody spoke and apparently they were like that all day. Dear me. (pause 3 seconds) It was horrible. I never saw the bedroom she had. I asked once or twice if I could go upstairs with her to see to her and they said oh no we will see to that. So I never saw it

3.Experiencing multiple losses throughout life
Loss of her family
(In the opening to her interview she spoke of the movement from her home where she lived with her sister, mother and son. Later in the interview it becomes clear that her sister and mother had died and her son now lives in New Zealand so she experienced loss of close contact with her son other than phone calls)
"We moved into the house that I left to move to this home in 1966 and there was my mum, my sister 'O' and my son 'P' and me. There were four of us. And when I left there was only me."

"It was they got the house and then they got a letter. (pause 4 seconds) anyway they ended up at New Zealand and they went over to , they did their two year stint in Australia because they had to and then they went to New Zealand because that is where they wanted to go to in the first place, but they still had to do the 2 year stint.
Both of their babies were born there. I'm talking now 23 year ago. 'H' is 23 and 'C' is 22 and they were both born there. But they wanted to be back in New Zealand, Christchurch and they have been there ever since."

"oh I think I will have another nap. They were the last words she spoke (long pause 10 seconds) That was the longest nap she ever had (chuckles) Half an hour later I went in to see if she wanted to get up and as soon as I looked at her I knew her eyes were just staring, brilliant green. She had green eyes but they were so bright."

Loss of employment
(She was made redundant and decided to take early retirement as she was unable to seek employment as her health was deteriorating)

"I retired because Parishes were closing down, oh that is right they were closing down and I had to retire because I was.. I got a bit of redundancy money. "

Loss of her physical well-being
She has arthritis, disc problems for which she had had surgery on 2 occasions and loss of visual acuity. (see 1 above)

Loss of a pain-free life
"Then I took another attack of crippling arthritis which they diagnosed later as arthritis in the spine. The surgeon I saw said there was no way could another surgeon go in to the back again. They had taken part of my hip bone out to put in my spine and he said you will not find a surgeon who would do that - it is a question of learning to live with it. The pain was atrocious."

Loss of her home
(When she made a decision to move to a care home this resulted in giving up the home that she had always lived in)
"I was in and out of hospital and then back home. They said I would need someone to look after me. It was a 5 bed roomed up and down house that I lived in. It was a lovely home. But I didn't want people walking in and out that I didn't know. I had an alarm put on and I thought they would be walking in and setting the alarm off. I didn't want that sort of home help and they suggested that I could move to a nursing home and this is where I moved to."

Loss of her vision
"My eyesight was going then. The doctor, the consultant gave me a kick in the stomach. After all of the test he said I am afraid you are one who slipped through the net and the only thing for you now is to register you blind. Well you know my stomach went down to my feet. What a way to put it. He could have been more gentle than that. The things went out of mind and I couldn't think of anything to say. I had a lump in my throat. You have slipped through the net, all we can do for you now is register you blind. Which he did and it has just got worse. It is funny. He diagnosed it as cataract, and a hole in the retina in the other. Other people in their 90's have had cataracts removed, can you not remove mine. No, there is a disease at the back of the eye. I have got a tape explaining it somewhere but I forgot what they called it. It is inoperable. When I look forward at a thing like that straight ahead I cannot see a ruddy thing. However, if I turn my head like that I can see the bird cage which is out of all proportion."

Multiple losses
- a gradual loss of her immediate family either through death or by living in distant lands
- loss of physical well-being
- loss of functional ability
- loss of independence
- loss of her home

4. Taking part in the decision to receive long term care in a home rather than at home
(When she experienced chronic ill health and needed long term support, the loss of her family network influenced the decision to move to a nursing home for long term care. In addition she didn't want to live in a situation where she was dependent on her family for long term care.)
The pain was atrocious. I was in and out of hospital and then back home. They said I would need someone to look after me. It was a 5 bed roomed up and down house that I lived in. It was a lovely home. But I didn't want people walking in and out that I didn't know. I had an alarm put on and I thought they would be walking in and setting the alarm off. I didn't want that sort of home help and they suggested that I could move to a nursing home and this is where I moved to. (short pause 3 seconds)

5. Care home staff have a key role in decisions concerning older people moving to their care home
(When Anne had decided that she would like to move to a particular care home an assessment was undertaken by the care home manager who had influence on whether Anne could move to home of her choice.)
"The matron was absolutely lovely – 'G' they called her. A nice woman. She saw me settled in. I had to go to somewhere down in Jesmond. She came down to my home. I had to pay £100 to this hospital in Jesmond. I paid £100. I had gathered up into a ball the doctor said and it was resting on the sciatic

nerve. This was causing all of the pain. She said that she was willing after she had assessed me, she was willing to have me in here. As it had only been opened a month."

6. Family and friends supported Anne to make and carry out decisions about choice of care home
(She was unable to visit homes as a result of her immobility so relied on her family and friends to visit care homes and provide information about them. They also shared their impressions of the home and this appeared to have a significant influence on her choice of home.)
"Because 'F' my friend, she has been a good friend, she had got in touch with 'P' (he came in the first plane over) and the two of them went looking at different homes. They saw one or two especially one in Raby street. It was in between two pubs. They shook their heads and just said no. There was another one they hadn't liked either and said no. And when they saw this pristine built they thought it was wonderful after what they had seen. So they said yes..... It was opened in 1986 in July."

7. Valuing opportunities to self-care
(In later interviews Anne talks about the importance of being able to do things for herself and being able to experience independence in some aspects of her life. When this transcript was re-read the topic of self-care was mentioned albeit briefly.)
"At least I can listen to stories. Stay in bed when I want to, get dressed when I want to. I do as much as I can for myself. That poor lady next door she just sits all the time. All she can say is Aye, Aye. She means no Aye, God only knows."

8. Knowing about the circumstances of fellow residents
(Though she has minimal interaction with fellow residents she knows who they are. This adds to the general milieu of the care home.)
"there was only 6 people in. I think they have all gone. No the lady next door (M), she can't talk bless her. She just sits there all day. At least I can listen to stories. Stay in bed when I want to, get dressed when I want to. I do as much as I can for myself. That poor lady next door she just sits all the time. All she can say is Aye, Aye. She means no Aye, God only knows. And the girls and the lad here, 'D' are so canny. I don't know how they keep their patience with some of them. Some can be a bit cantankerous. Please God may I never get that way. Touch wood. But I feel so sorry for 'M'. The family comes to her mind. I do say they rally around her. They come and visit her a lot."

9. The importance of personal activity/interests
(Being able to do something that she found interesting and pleasurable in the care home was important to her)
"At least I can listen to stories."
"If it wasn't for these talking books that I get from the RNIB I would be crackers. I would be out of my mind."

10. Visual impairment results in difficulty in developing and maintaining relationships with fellow residents
(Her visual problems led to difficulty in establishing and maintaining relationships. In this quotation she indicates that she is not a good mixer. Her story about her earlier life is one of an outgoing sociable woman. Maybe she is pointing her to the problems she faces when trying to mix with others who are living in the care home. She faces continual embarrassment because she is aware that she continuously breaches normal social conventions when she fails to acknowledge others following initial introductions and discussions. To compensate she withdraws to her taped-books and avoids contact with other residents. In contrast she seeks to develop relationships with the staff - maybe she feels that they understand the difficulties she experiences as a consequence of her visual limitations)
"Cause I am not a good mixer. I'll tell you what happens. I used to go down to the sitting room which is beautifully decorated with lovely armchairs and lovely furnishings and photographs. Really nice you couldn't get it more homely. They keep changing things around which makes things worse for me. Never mind. They will introduce me to somebody and I can sit and talk with them for a little while, not very long. I can't always understand what they are saying. And the next day, I wheel myself straight pass them and they think, she's a bit stuck up there. And they don't speak to me and I don't speak to them (laughter) We are like bits of kids, oh dear God. To think that I have come to this. I have been talking to a woman for ages and the next day I wheel myself past her because I cannot see her and I don't recognise her."

11. Desiring communication with staff who are too busy to talk
(Anne looks forward to the time when staff talk to her about their family, interests and events in their life. Unfortunately they always appear to be rushed. Anne argues that they need to give timely care to residents but she would really like them to set aside a little time to talk to her.)
"The girls I have to get used to their voices and recognise them by that or their outline if they stand still long enough. That is seldom, they are always so busy. They are so busy, that is one thing I would like to see an improvement made on - if, which I don't think will ever happen because they are always so busy. If they could only find time for only 10 or 15 minutes conversation per week to sit down and say I am here 'S' we can have a little natter. Just to sit and talk to somebody like I am talking to you, but this is nearly all about myself but I would like to hear them, what is happening outside. "

"That is the only thing I would complain about. I don't complain because I know that that is impossible. The staff situation, they can't cope with that sort of thing, that's asking too much a one to one conversation. But even once a week would do, you know. I would not expect it everyday but apart from that it is great."

12. Knowing what is happening in the staff world
(By observing staff in their daily activities and listening to their conversations Anne builds up a detailed knowledge of what is happening to the care staff. She knows what they do, when they are on sick leave, the reasons why they leave the home.)
"The activity lady she is off. She has just taken the job over. She wasn't trained, she was going to start her training to be an activities person. She broke a bone in her hand and now she is on the sick. What with the weather that we have had, how some of them got into work I do not know. But they did. Some had to phone in sick when they had the flu. Some had a fall on the ice and they could not get in. Poor 'D' he comes from Alnick and he never missed a shift. He got stuck in Morpeth once when the snow was so bad."

Appendix five: Diary notes recorded during Anne's sixth interview and Anne's interpretation file from interview 6

Interview 6: 25.4..01

Initial reflections following the interview
Anne was ready for my visit today and she appeared to be in control of when social conversation would cease and the interview itself would commence.

There had been considerable changes in the home – new carpet, changes in staff and she took the opportunity to talk of these changes in relation to her own personal situation.
Anne was much more relaxed and desiring to explore a range of issues in the interview.

There had been many unexpected circumstances occurring during the previous fortnight. Some were undesirable - there was a flood in the kitchen which led to problems in cooking; a robbery (the matron had her bag stolen). Whereas other events were desirable - the home was in a process of refurbishment and a new carpet had been laid in all public areas of the home.

These events occurred at a time when staff were leaving and being replaced therefore the transience of staff continued to be a dominant issue discussed throughout the interview.

The residents and relatives meeting had taken place on Tuesday. Anne had forgotten about this meeting and was reminded by a staff member short after it had commenced. She declined to join the group at this point and continued to be concerned that this was going to turn into a "grumble" session rather than a productive discussion group. She might attend the next meeting.

Issues:
Situations where Anne actively made contact with others living and working in the care home

- Initially Anne indicated that she does not make contact with others other than chance or functional meetings (i.e. passing in the corridor) as a consequence of the physical limitations she experienced in interacting with others.
- Most activities are sole and carried out in her room – i.e. listening to the talking books, having time with her friend on a Thursday
- Functional contact with staff (S Oh yes but not as much as I would like as I have told you before. They haven't got the time to come and sit and have a one to one. To have even a 10 minute conversation. They pop in for dishes and to bring you your food. Things like that. The hairdresser usually comes in before she goes and has a cigarette with me. That's nice, I like that. Only on a Tuesday. she is only in long enough to smoke her cigarette, about 10 minutes if that and that is nice. And here is one of my favourites)

  (R Do you still go down. when you went down to collect your post you used to have a chat with Helen and Anne

  S Only if I have business to discuss

  R So alright it wasn't conversation

  S Oh no. I mean they will if I go down and they shout come in. Well obviously you cannot open a door when you are pushing a wheelchair and they will open the door and say hello Anne how are you la blab. Hold on a minute and I will see if there is any post for you and that's it and out I have to come. Its just not the time for them to sit and talk. But as I say it is not their fault)
- Maintaining friendships is really important (Then I have my friend on a Thursday night and she never fails bless her. That is always something to look forward to. We have got the same warped sense of humor.)
- She observes the way that other residents interact with each other (There is a lady called Anne and I haven't seen her for at least a week . I must ask how she is. She made friends with Nancy and it was lovely to see them walk past, hand in hand. And it was so nice and they used to call for each other and it lasted for about 6 months I would think.)
- The death of fellow residents is painful particularly when they have become close friends in the care home (She was devastated poor soul when she lost her friend (Ann and Nancy). She has got it into her mind that everybody is against her now. I don't know why. She says I will not do that again and they can say what they like about me.)

Factors affecting the development of relationships

- Transience of staff
- Staff workload
- Avoiding the pain of loss when other residents die

Story files:

1. Son's birthday
2. A flood in the kitchen
3. Theft in the home
4. Missing a residents'' meeting
5. Changing staff roles
6. The Easter fayre
7. Why staff leave the home
8. A thick-piled carpet changes life in the care home and decreases opportunities for self-care
9. Difficulty in communicating with new or transient staff
10. The talking-books
11. Wanting to talk to the staff and getting to know them
12. Staff are too busy to chat
13. Problems understanding fellow residents
14. Chatting to neighbours: a case of personal preference
15. Ways of avoiding fellow residents
16. A welcome visit from a friend on a Thursday evening
17. Other residents' visitors
18. The pain of loosing friendships in the home
19. Being at home near a train line
20. Calling the care home 'home'
21. Feeling like returning home from hospital
22. Moving rooms in the care home
23. Getting to know about care homes through family and friends
24. The importance of personalising personal space
25. Why staff leave the care home
26. Staff keeping in touch when they leave the care home
27. Knowing about other residents going on trips from the home.

Topic files: Reflections following transcription

1. Importance of maintaining contact with family and friends

(Anne had been talking about 'Ps' birthday when I first arrived at the home and she was excited about receiving a phone call from him when she would hear of the events of the day. Later in the interview she spoke about looking forward to the regular visit from her friend.)

"**R** So it was 'P' birthday

S Yes. It will be over now, it will be 2 o'clock tomorrow morning. I hope he has had a nice day. He always has a holiday on his birthday because it is Anzac day.....Australia and New Zealand Army Command, is the C for command."

"Yes, that's true. Then I have my friend on a Thursday night and she never fails bless her. That is always something to look forward to. We have got the same warped sense of humor."

2. Negative events are unsettling

(Many events had happened in the past 2 weeks. There had been a flood in the kitchen and this resulted in the kitchen being refurbished. Also a roll of carpet was stolen from the foyer and the matron had money taken from her bag. Anne knew of the details of these events and she felt a little unsettled by them. She felt that these events had created distrust in what had been perceived as a safe and trustworthy environment.)

" Well yes, it leaves a nasty taste in your mouth it does really. I think it has been an inside job from their end. They had a van and they just dropped it off. They couldn't have got it in anybody's car. No, no way. Matron £30 and all her credit cards of course. But she had to stop them immediately and it will takes 4 - 7 days before she can get any money out.. There is one thing there is never a dull moment in this place."

3. Residents can influence what occurs in the care home
(An advocacy group had been set up in the home. Anne had been invited to the meeting. She felt that residents influence or indeed complaints should be up front and taken directly to staff.)
"Do you remember what I was telling you about the group thing they were trying to set up. I forgot all about it and no-one reminded me. Did they? Not until it had started and matron came along and said are you not going to the meeting and I said what meeting. She reminded me on and I said I forgot all about it 'E' and I can't be bothered it will already have started and I said if it is going to be just a complaints thing I am not interested. They should have gone to you. There is no staff going to the meeting and that to me is just ridiculous. It is just going to put a wedge between the residents and the staff I think. That's my opinion it is just like going behind somebody's back isn't it. I said that to 'E' and I said oh no if they are not satisfied they should have come to you with their complaint. Not to discussion groups. That divides the staff from the residents - well 'D' what do you think she has been saying about me. You know. Its only natural, only natural. However I haven't thought anything about the meeting. There is another one in about a months time so 'E' is going to let me know what it is about.
R I thought they were going to talk to the matron at the end?
S Well I haven't seen matron today so I don't know if they did that or not.

4. Importance of the relationship between residents and staff
(Anne had some concerns about the impact of the advocacy group on resident staff relations in the home. She felt that relationships between residents and staff were similar to relationships within a family unit.)
"There is no staff going to the meeting and that to me is just ridiculous. It is just going to put a wedge between the residents and the staff I think. That's my opinion it is just like going behind somebody's back isn't it. I said that to 'E' and I said oh no if they are not satisfied they should have come to you with their complaint. Not to discussion groups. That divides the staff from the residents - well 'D' what do you think she has been saying about me."
"You've got to get closer together not more distance between you. At least I think that."
"I think the staff and the relatives should try and get together and be friendly. And helpful. Well they are, some of them. Most of them are."

5. Transience of staff in the home
(Anne often talks about staff leaving the home. The staff turn over in the home appears to have increased during the latter interviews in the sequence. Some staff only seem to stay in the home for a short period of time and this makes it difficult for Anne to get to know them)
"Well I mean you are with them every day if they last long enough. Some of them are only here a fortnight. We have got another one leaving this week."
"It is possible I suppose but you never get that opportunity. You don't. Its either the staff you like they leave - they are never here 5 minutes."

6. Knowing what is happening in the staff world
(Anne readily talks about what is happening to the staff – the movement of staff in and out of the home, sickness and events in their lives. She has thoughts about the reasons why staff leave the home and views about this.)
"She is in today and she was in yesterday because she does the shampooing when the hairdresser comes in on a Tuesday. But they cut her hours so far back that she says it is not worth her while. She came as a cleaner and then she got to carer and she was trained as a carer and then the activities person left and she was given the job and said yes she would like to attempt it. right we will make the arrangements for some teaching where you get taught about how you go on about it training places. And I don't think she ever got to one and then she was poorly - she broke her hand, that was it. She was off and when she came back they cut her hours and said that it wasn't necessary. So we have got no activities going on."

"'N' told me on Sunday, no Monday. "S' I am leaving." I said "Oh you are not 'N'." She said "Oh I am". She says "The money is no good they have cut my hours." She is waiting for some benefit to come through but until she finds out how much it is going to be. But if she still leaves I don't know. But I think she still will because she is fed up
R Why is she fed up?
I don't know. I don't think she gets on very well with the matron. I think that is the trouble because she keeps saying oh I wish 'S' will come back. Wish 'S' will come back and you can tell from words like

that that she is not getting on so well with the new one. But you can't like everybody in the world can you pet.
R Too true."

"No she had left. She was here about a year and she got a home up at Alnwick. And she wouldn't have left but we had a terrible winter with snow and ice, 4/5 years ago. She lived at Morpeth/ Rothbury which is beyond Morpeth. It was terrible driving conditions she had to go through. The length of the journey to get here and go home at night. she couldn't stick it any longer. She wasn't young. Well she was young compared to me. She got a nursing home in Alnwick. I have heard from her since. She sends me a Christmas card every Christmas. That's nice as well isn't it?
R Is she the only one who has ever done that?
Yes. And she is now area manager up there. So she will have left that home and goes to others that are up there. I don't know how many homes she has got. But that is what I have heard anyway."

7. Limited activities in the home due to staff illness and staff changes
(What happens in the home is highly dependent on the availability of staff. When they are absent or when staff leave this has a noticeable impact on the activities programme in the home.)
"She came as a cleaner and then she got to carer and she was trained as a carer and then the activities person left and she was given the job and said yes she would like to attempt it. right we will make the arrangements for some teaching where you get taught about how you go on about it training places. And I don't think she ever got to one and then she was poorly - she broke her hand, that was it. She was off and when she came back they cut her hours and said that it wasn't necessary. So we have got no activities going."

8. Special regular/annual events in the home are a positive feature in the home's diary
(Anne gave detailed descriptions of organised events in the home. She indicated that she looked forward to these and took great interest in the planning and the occurrence of these events.)
"Apart from we had an Easter bonnet parade on Monday and I don't think I have seen and Easter bonnet yet which was rather disappointing. Last years was beautiful. All the staff helped to make them you know
R Yes
For the residents and they were sitting in their wheelchairs with their little hats on and there was prizes give. But this year there was not a hat in sight so what happened I don't know. But they had a raffle and guess the chicken name. I don't no who set the names but I got Butterbun. The name of a chicken. I have heard some names for things but never Butterbun
R No I haven't heard that one before
No I haven't definitely haven't. Then there was a glass of wine and a buffet tea. There was a few relatives came but it was 3pm and that is not an easy time for relatives you know. Other times it is 6.30 and that is not an easy time for other relatives. You cannot win. There didn't seem to be a lot their last night. They had it in this top lounge. It is a lot smaller than the dining room where they had the last one."

9. Good staff – relative relationships are important to residents
(Whilst Anne referred to the importance of good relationships between staff and residents she also pointed to the importance of good interaction between staff and relatives.)
"I think the staff and the relatives should try and get together and be friendly. And helpful. Well they are, some of them. Most of them are."

10. Experiencing continual loss in her life in the home
(Different types of loss, of independence and bereavement, are described. Loss is an inherent part of life as a care home resident)
Loss of independence as a result of the refurbishment of the care home.
(The new carpet that had been selected for the public areas of the home had a thick pile. One of the first areas that this had been lain was the room where hairdressing was carried out. Anne had her hair styled every week so she was aware that the new carpet was more difficult for her to manoeuvre her wheelchair due to the increased friction between the floor covering and her chair. When the carpet was lain in the long corridors of the home she was no longer able to wheel herself to the front door to collect her post, and she required the assistance of staff to move in these areas. Therefore she felt that she had lost a little more of her independence that was due to the physical environment of the home rather than a deterioration in her health.

"I think they have done upstairs. But as I told you it is terribly well I suspect it will be heavy to push your wheelchair
R Is it
The pile is too thick, piles too thick. I don't know how the lasses manage 12 hour shifts pushing wheelchairs and trolleys back and forward I don't know how they mange because it must be heavy on their legs. I mean its not a flat faced pile like this one I mean there is pile. I managed to get down but I couldn't get back. I was exhausted so I had to wait until somebody was free to push me back
R How do you feel about it
Well I have lost a little bit of independence again, haven't I? I am used to loosing a little bit every now and again. Now I have to ask somebody to push me back. Well before on the other carpet I could just wheel down and wheel back with about 5 minutes rest at the other end. I used to like to go down and collect any post like tapes and things that were down there for me in the mornings. And sometimes they are too busy to bring them up and I used to enjoy that because it was something that I could do for myself. But I can only mange one way. Never mind I will get used to it I suppose.
R Did you discuss it with them
Well I mentioned it and it was well God knows how long we have had the carpet on order because they have been talking about it for long enough. And I did say I hope that the pile is not too deep. they are experienced owners and they should know that sort of thing. wouldn't you think. You think they would know that. That is probably why they put that sort of thing in (pointing to the existing carpet) the last owners when it was built. They had known. If you go there and feel it
R Well I did when I was walking down
Well there you see. well you try pushing a wheelchair. Oh dear I am grumbling again. what an old natter box I am getting.....I am just describing the way it is."

Loss through death and bereavement
(Anne spoke poignantly of the death of fellow residents. She implied that death is a feature of a care home that residents will encounter, and this is particularly upsetting when residents have become friends.)
"There again some of them are not here long enough to get to know I suppose. There is a lady called 'A' and I haven't seen her for at least a week . I must ask how she is. She made friends with 'N' and it was lovely to see them walk past, hand in hand. And it was so nice and they used to call for each other and it lasted for about 6 months I would think. and then 'N' died and poor 'A' was absolutely lost she was devastated. I thought to myself I met her in the foyer one night when I was waiting for 'F' and she got onto talking about 'N'. She said "I am never ever going to do that again," and I said "What are you never going to do"? She said "Get friendly with anybody in here because they all die". Well I felt like saying that is what we are here for and this is the place to do it. She must understand that but I didn't want to upset her. She was devastated poor soul when she lost her friend. She has got it into her mind that everybody is against her now. I don't know why. She says I will not do that again and they can say what they like about me. I am not going to let in worry me. And that was the end of that cheerful conversation."

11. Endowed expertise
(Anne assumed that care staff have knowledge of the impact of the environment and care on the lives of residents. They were experts as care providers and as such they ought to know the thick-piled carpets on the floor had the potential to limit wheel chair users ability to move their chairs without assistance. She appeared saddened through her increasing awareness, that the staff who she believed had expertise in providing and creating a care home, had not predicted the effect that the new carpet had on the functional ability of residents.)
" Well I mentioned it and it was well God knows how long we have had the carpet on order because they have been talking about it for long enough. And I did say I hope that the pile is not too deep. They are experienced owners and they should know that sort of thing. wouldn't you think. You think they would know that. That is probably why they put that sort of thing in (pointing to the existing carpet) the last owners when it was built. They had known. If you go there and feel it."

12. Communication problems impede interaction between residents and between residents/staff
(Interaction between residents and other residents and staff is greatly influenced by their ability to communicate with each other. The other factor that limits communication in the care home is time – time for the staff to stop and talk to residents. Consequently most of the interaction between staff and residents is short and focused on the purpose of the interaction.)

"Sometimes I can't understand what they are saying. I have got the ear phone going up and down like a yo-yo to get the sound. If they have got an accent I cannot understand them. Like we have had 3 coloured people in this week cleaning and caring. Very nice friendly people but I couldn't understand a word they were saying. But if I see them again the next day I can't remember them, I can't recognise them by voice. I recognise the staff here by voice when they have been here a while you know. But if I just talk to them for a few minutes in the foyer when I have been down there I can meet them the next day I wouldn't connect who that was."
R "In what situations do you seek contact with others in the home
Well I don't think there are any. I never bother with anybody. I have always been on my own and I like being, I have always been a loner. Well I can't see them properly 'G'."

"I dare say I could go and sit next door but the lady cannot talk and I cant understand her, what she says. Lillian over the road, the one who is always on the buzzer I don't understand a word of what she says."

"Oh yes but not as much as I would like as I have told you before. They haven't got the time to come and sit and have a one to one. To have even a 10 minute conversation. They pop in for dishes and to bring you your food. Things like that. The hairdresser usually comes in before she goes and has a cigarette with me. That's nice, I like that. Only on a Tuesday. she is only in long enough to smoke her cigarette, about 10 minutes if that and that is nice. And here is one of my favourites."

13. Different levels of interaction between residents
(Anne describes different types of interaction between residents. Some relationships characterise that of friendship whereas other relationships are more in the form of neighbours.)
"Well I never have been one, neither has my family of being one who is running in and out of each others houses. I couldn't stand that. we would speak to each other and always be there to help each other if we needed it but not over the garden fence sort of style. We have never had that sort of relationship."

"There is a lady called 'A' and I haven't seen her for at least a week . I must ask how she is. She made friends with 'N' and it was lovely to see them walk past, hand in hand. And it was so nice and they used to call for each other and it lasted for about 6 months I would think. and then 'N' died and poor 'A' was absolutely lost she was devastated."

***14.** Avoiding contact with others*
(Anne avoided contact with fellow residents by remaining in her room and engaging in solitary activities.)
"I suppose by staying in here. I just stay and listen to my stories. That's avoiding everybody I suppose."

15. Familiarity is an important feature of the environment
(There were features of the setting of the home that she moved to that were similar to those of her home – both places were near railway lines, both had the number 20. These features were important as a way of being familiar to the setting that she was living in.)
"No it is funny I have always lived near a railway. there used to be one at the bottom of the street, about the length of this corridor. It never bothered me.
R Do you quite like hearing it in the background
Yes, reminds me of home I suppose
R Do you ever think of this place as home Anne
Now I call it home, yes. ???say when they push you back in when you are going to the bus library and I get all my books in carrier bags - they have got a lift which gets you into the bus. They have a thing that they push your chair on. ???I say thank you very much but I have to get back home now. I t just comes automatically now and yet if I talk about my own home I would say where I lived - my own home. I call this home now. Well after 6 years you have go to. Nearly 6 years anyway."

"Yes if you look in the other rooms you will find they are not as big as this. There is not a lot of difference you know. But it is this and number 20 and it was funny. 20 was empty when 'P' and my friend 'F' came around to have a look at it. They had been to a few and the social worker said that there was a new one in Forrest Hall that I would like you to see. She picked them up in the car and brought them in and of course as soon as they saw it all pristine, new and everything. It was lovely and this one

and number 20 upstairs were this size. 'P' said that this was a nice big room. So 'G' said straight away that it will be 'S' if she wants it when she comes back. And he said oh that will be nice. So it was a toss up between this and 20. I moved into 20 because I lived in 20. She stood like that with her hand on the door and she said have you seen the number on the door 'S'. I said "No I didn't," and he said "Oh its 20, you win. Put her down for 20". However it was number 1 because it still wasn't full downstairs. Before they started filling up upstairs. And that was it and I have been here ever since."

17. Importance of personal possessions in personal space
(Though Anne spoke of familiarity with her environment she also pointed to the importance of being able to have her own possessions in her own room.)
" Then I was in hospital a month and when I came back all my things had been moved in and my own bed. Nobody else had slept on this bed in was brand new. It was a hospital bed. I had all my bits and pieces. It was like coming back into a home you know when I was seeing my own things. That was nice."

17. Family and friends supported Anne to make and carry out decisions about choice of care home
(Retelling the story of selecting the care home that she moved into – this was also addressed in interview 1.)
"Yes. Well that was a dilapidated state of a place. It was terrible. And they sent them to this home, not a nursing home it was just a house. there was a pub on that side and a pub on this side. And when you sent in the smell apparently had been so terrible it nearly made them sick. So 'P' said lets get out of here. My mum is not going to come in here. 'F' says "I wouldn't let here come in here". So they went back and played hell with the social worker that had sent her there. They said it was absolutely disgusting. Apparently it is still there. It used to be called Brinkburn St. No. It was on the left hand side in between these two. She said could you imagine them all coming out at night time. When the pubs empty. She said no way is she coming here. So they went on looking and came to 2/3/ places. But as I say this one, being new. Naturally they went for this one."

17. Kindness enhances the quality of Anne's life
(For Anne the little things that staff did, over and above the care and support that she needed enhanced her quality of life in the care home.)
"When I came back Matron bought me a tiny little cactus plant. welcome home it said on a little card from matron and staff. That was a nice gesture. You see little things like that touch me. you know. Its just the little things that make it so bearable. That was a lovely gesture. And another thing. that touched me was. There is a red rose somewhere.
R Yes there it is in a vase.
Yes it is a paper one, plastic one. And we all got one of those on St Valentines day about 4 years ago I thought that was nice."

"Nice person 'G'. And then we got a chocolate egg at Easter. That was nice. It is little gestures like that that make it nice. They had a trip out to the Metro Centre."

18. Being able to choose activities is important
(Anne indicated that she was invited to take part in activities but she also had the choice to take part or decline to do so.)
"That's right. They had enjoyed it apparently. I went to the first trip there during the first year I was here but I didn't like it. I didn't like it a bit. So when they asked if I wanted to go back I said no thank you.
R Nice to be given a choice though.
Yes. "

19. Knowing about the circumstances of fellow residents
(She was aware of what other residents were doing in the care home.)
R "Oh when I was looking for 'G' they said oh she has gone on the trip.
That's right.
R Well it got to 3 o'clock and I thought that she would be too tired to talk with me. So I made an appointment to come back last week. There is no point if she is tired after being out all day.
Oh no. I think they slept in the lounge when they came back. They all fell asleep.
R There is a large crowd in the lounge at the minute.
Is there?

R Yes I think there has been a lot more new folk.
Yes. They come and go. I don't know if they have got the carpet down or not."

Appendix six: Transcript of Anne's first interview

Story - lines

Topics

Interview 1
Resident interview: A/1
16.2.01

S Well my life is not very interesting I don't know where to start. We moved into the house that I left to move to this home in 1966 and there was my mum, my sister 'O' and my son 'P' and me. There were four of us. And when I left there was only me.
Fortunately 'P' is still alive and he lives in New Zealand (pause 2 seconds) I (pause 3 seconds) 1962 I had a laminectomy. I don't know if you know what that means (quiet monotone voice)

R Is that where they remove the disc from your back

S That's right. I was in and out of plaster casts for months before the operation. But never mind they finally operated and everything went fine.
And I worked at GT Parish as a buyer (pause 2 seconds) and everything was going swell when in 1962 another disc went oh it was 1968, 62 was the first time (pause 2 seconds)
once more I was in and out of plaster and traction and what have you and then Mr 'T,' the surgeon decided yes we could do a spinal fusion (raised voice) so the um he took me in and I was in for nine months till I got made better. It was the most wonderful day on God's earth when I walked because with operating in the same place they were not terribly sure of the end they gave me a 50, 50 chance. And I took it and I thought well why not (pause 1 second) and then after I was in a plaster bed, a carpenter made the bed. He used to turn me every so often on a big machine - they used to put it in on like a sling, they used to whip me onto there, wind it up, turn me over face down and how would you like that for a few hours, which wasn't very pleasant I can tell you (change of tone and speed of voice)
Never mind it got over and I came out and I had a wonderful boss - Parish you call him, absolutely wonderful. (pause 4 seconds) He paid for the convalescence. For me and for my sister to come and look after me. Wasn't that a wonderful thing to do?

chronic ill-health - Spinal problems

2

R Yes

S because by then I was working in the office after 62's operation I couldn't do much standing about which you have to do in the show room. So we both went off to Tenerife and left my mum and son to look after each other. Which they did very well apparently.
However, we got over that it was wonderful to be able to walk, on crutches first and eventually normally. (long pause 6 seconds)

3

4

While I was in hospital at the time during 68 my mum fell and broke her hip. Well she was in the General and I was in Sanderson (pause 2 seconds) and my sister and 'P' were running in and out between the two hospitals visiting because the hospital as you know has visiting hours. Sanderson was like here where you could visit any time. So I had a word with my doctor, doctor. Well I had a word with my doctor to see if she could get her transferred to Sanderson and we went through all the arrangements and we got her there so there was only one hospital to visit the two of us which was a great help for them.
And ah (pause 2 seconds) when we came back to work which I thoroughly enjoyed (raise tone in voice and increased speed of delivery) . I worked in Parishes for 30 year. (pause 2 seconds) and then I retired.
Towards the end when mum was 96, she had senility, that took over and her mind was completely gone. She had a terrible two years those two years. She was always on fire, surrounded by fire. We brought her bed downstairs so 'O' would not have to run up and down because she was retired by then, was she, No not quite. Anyway we brought the bed downstairs for mum and the houses across the street were on fire the bed was on fire. She was in as many different hospitals for so many weeks and then they would transfer her here and there. She was in the General I don't know how many times. They even had her in the Clinic which was near here and was the cracker clinic. I don't know if you have heard of it or not.

Caring for others - co-ordinating her mother's care

5

R Yes I have

S She was in there 6 weeks poor soul and she must have been on every drug she must because she never spoke when we went to visit her. She was just like in a cocoon wrapped up in the sheets lying on the bed. Never mind that lasted 2 years and she finally died. The week before she died she was home. They took her in hospital on the Friday. On the Friday night when I came from work 'O' says oh

she says she is away the weddings on, cause he was getting married the next day. And she went through it all and she says that is a nice hat you have got on. You look very very smart. You know what mums are like. Even if you were the ugliest bairn on earth you would be lovely to her and she was full of the wedding and she went right through. Oh hello 'E' and oh hello 'J' and oh hello so and so. The names were coming all out about the guests. And 'D' my son's fiancée. She was unbelievable (chuckling and her face was animated) Through the night she was back to where she had been. They took her back again into hospital and she missed the wedding. Wasn't that sad? It was for her anyway. (pause 3 seconds) dear me

5

They put her in a home once. (long pause 6 seconds) It was a terrible place (her voice changed to a low tone) It was an old broken down big house in Jesmond. The garden wall was lying in the garden. Now when you opened the door the smell was atrocious. (pause 4 seconds)

Negative experience of care home

So they took us into a big long room with two rows of chairs facing each other with a space between them for the wheelchairs to go through. I never saw any wheel chairs in that home. And they just sat there facing each other. Nobody spoke and apparently they were like that all day. Dear me. (pause 3 seconds) It was horrible. I never saw the bedroom she had. I asked once or twice if I could go upstairs with her to see to her and they said oh no we will see to that. So I never saw it

6

And then skimming a lot of years 'P' and 'D' went off to Australia and then New Zealand. They did a two year stint as they promised to do. It was when the £10 fare was on you know. They took advantage of it because they had wanted to go there all along. Actually he was saving up to go and this £10 scheme came out and they went down to London to have an interview with the Commissioner. And however, they got turned down. They said well that's it we will buy a house and stay. So they started to buy a house up in Cramlington and a year later they had a letter from the New Zealand Commissioner. Oh I am mixed up with my story, which was the first time. It was they got the house and then they got a letter. (pause 4 seconds) anyway they ended up at New Zealand and they went over to , they did their two year stint in Australia because they had to and then they went to New Zealand because that is where they wanted to go to in the first place, but they still had to do the 2 year stint. Both of their babies were born there. I'm talking now 23 year ago. 'H' is 23 and 'C' is 22 and they were both born there. But they wanted to be back in New Zealand, Christchurch and they have been there ever since.

7

loss of close contact with her son

I have been out twice to see them, but unfortunately, well fortunately my sister was with me (long pause 8 seconds) and 'D' and 'P.' I had booked up a holiday in Southland I think. Or is that Australia? South something - it was about a 100 miles away. But they had given us a week to settle down and get over the jet lag you know and off we went we got there on the Saturday.

8

When we woke up on the Sunday morning 'O' says oh I am so tired so 'P' says why don't you go back to bed and we will take the kids up to the play park. (pause 5 seconds) They weren't away half an hour and she died - well that was a heck of a shock. (long pause 8 seconds) I was talking to her half an hour before. She says oh I want to go to the toilet and I said come on then. and I said do you want any help and she says no. She came out the bedroom and across the living room and into the bathroom and went to the toilet, she washed her hands, dried them and walked back to the bedroom. She said I think I will get dressed and then I said oh have another half hour because you had wobbled a bit on the way back and she was leaning on my arm and I tucked her up and she says (pause 3 seconds) oh I think I will have another nap. They were the last words she spoke (long pause 10 seconds) That was the longest nap she ever had (chuckles) Half an hour later I went in to see if she wanted to get up and as soon as I looked at her I knew her eyes were just staring, brilliant green. She had green eyes but they were so bright. I ran out for the caretaker or janitor and a funny thing he was coming down to see if there was anything we needed and I told him - oh I think that she is dead and he rushed in and got on the phone straight away and got the paramedics. They came rushing in and I could hear them putting her on the 'F' or with a thump and they started then artificial respiration of whatever you call it. They started that I could hear them hitting her on the chest or somewhere because I was in the other room. They came out and said that they had to have a doctor. The janitor was still there and he rang the doctor and within minutes the doctor went in and he came out again and he said oh I am sorry. I said she is dead isn't she and he said yes. The janitor asked where the family was and he said I will go and see if I can find them in the park. By then I was just a mass of tears. That was a terrible time (long pause 10 seconds)

Death of her sister

9

Loss of he only sister

They had to take her all the way down to the bottom of New Zealand - I have forgotten what they called the place - for a postmortem because we were strangers in the country, just on holiday. They had brought the police in and we had to go through all the questions about where we were from and what we were doing here. How long we expected to stay and lots of questions. How long had she been ill and did she have heart trouble before. I wouldn't care we had a medical to see if we could fly because

she was 19 year older than me and that made her 77. Her own doctor had checked her over and said that there was nothing wrong with her that she couldn't fly. They took her all the way down the bottom of New Zealand for the postmortem. We were left and we came straight back to 'P''s and they were very nice in the place we were staying and they didn't take any money or charge 'P', they even gave 'P' his deposit back. It was very generous of them when I realized what they had done after.
We had to ring home because my brother who was looking after my house because we had a dog. Now we had to phone them up and let them know. We had the funeral over there. She was buried there because it was going to cost so much money to bring her home. We buried her out there. She wanted to be buried and not cremated; it was too expensive to be cremated. I'll never have no money left to do it. Never mind that is another world.

Oh dear (long pause 12 seconds) it was terrible, it was terrible. So after they went home I was left on my own and that was that (very quiet) when was that 1984 / 1988. What was 77 from 1906? 1983 It was then and then....(long pause 8 seconds) I am getting all mixed up. 1983 / 1984 I retired because Parishes were closing down, oh that is right they were closing down and I had to retire because I was.. I got a bit of redundancy money. I must have retired before that because it was the redundancy money that paid for the trip. Do you want me to stop??

10
loss of employment

R No

S I had my redundancy money because it did pay for the trip so we could afford it. 1984 That's right when I came home I was on my own. 2 years later 'P' paid for me to come out again. It was the most terrible journey anybody ever had. We had a thunder storm going over, when we reached the date line, I thought the plane was going to hit the ground. We went whoosh and then up again and then whoosh (hands moving demonstrating the movement). Oh it was horrible. I was on my own , no one to talk to. Terrified, but never mind we made it and 'P' was waiting for me. And then we got the plane over from Auckland to Christchurch. I never knew a landing strip so close to the ocean I thought he is never going to hit it. (laughing) I thought he is never making it and we will land in the sea. 'P' says don't worry we will make it. We were going down and down and he came up and we circled. That was a terrible journey getting there. We were 9 hours late leaving Heathrow, we couldn't land there he had to go to Gatwick and he said he was running out of fuel. What a damned stupid thing to say. After the journey we had, we got through with the storms and everything; we have only got enough petrol, fuel to get to the other airport. So we had to stop circling that airport and go to the other. We landed there and everything was grounded. I think we were the last plane to land I don't know what happened to the others. Then we got transported back by bus to the first airport and we had to get all the luggage out again and stack up this coach at the other airport. Then we had to go to Stanstead. So you can imagine what it was like when I got to New Zealand. 'P' just threw his arms around me and I said I've never been so glad to see you in all my life. He listened bless him and he said come on lets go and get a coffee and then we will get the next flight to Auckland. (short pause 3 seconds) I was there 6 weeks and came back to an empty house.

11

My dog was a great help (pause 5 seconds). Then I took another attack of crippling arthritis which they diagnosed later as arthritis in the spine. The surgeon I saw said there was no way could another surgeon go in to the back again. They had taken part of my hip bone out to put in my spine and he said you will not find a surgeon who would do that - it is a question of learning to live with it. The pain was atrocious. I was in and out of hospital and then back home. They said I would need someone to look after me. It was a 5 bed roomed up and down house that I lived in. It was a lovely home. But I didn't want people walking in and out that I didn't know. I had an alarm put on and I thought they would be walking in and setting the alarm off. I didn't want that sort of home help and they suggested that I could move to a nursing home and this is where I moved to. (short pause 3 seconds)

chronic illness
loss of a pain free life
12
loss of independence
loss of her home and choosing care.

The matron was absolutely lovely – 'G' they called her. A nice woman. She saw me settled in. I had to go to somewhere down in Jesmond. She came down to my home. I had to pay £100 to this hospital in Jesmond. I paid £100. I had gathered up into a ball the doctor said and it was resting on the sciatic nerve. This was causing all of the pain. She said that she was willing after she had assessed me, she was willing to have me in here. As it had only been opened a month. Because 'F' my friend, she has been a good friend, she had got in touch with 'P' (he came in the first plane over) and the two of them went looking at different homes. They saw one or two especially one in Raby street. It was in between two pubs. They shook their heads and just said no. There was another one they hadn't liked either and said no. And when they saw this pristine built they thought it was wonderful after what they had seen.

a care home was Anne's decision
The matron has
13 the final Si
F+P keeping
A informed about / informed re. care home

So they said yes..... It was opened in 1986 in July, there was only 6 people in. I think they have all gone. No the lady next door (M), she can't talk bless her. She just sits there all day.
At least I can listen to stories. Stay in bed when I want to, get dressed when I want to. I do as much as I can for myself. That poor lady next door she just sits all the time. All she can say is Aye, Aye. She means no Aye, God only knows. And the girls and the lad here, 'D' are so canny. I don't know how they keep their patience with some of them. Some can be a bit cantankerous. Please God may I never get that way. Touch wood. But I feel so sorry for 'M'. The family comes to her mind. I do say they rally around her. They come and visit her a lot. (pause 3 seconds)

Self-care

14

Circumstance of fellow residents

Of course 'P' had to go back home naturally and 2 years later all 4 of them came over for a holiday. It was the first time I had seen my grandchildren for years. Other than the last time in 1984. They were teenagers the next time I saw them, 18 or 19. In 1994 was it 1994 , oh I forget what date. Never mind. I saw them which I was thrilled to ribbons. The kids could only stay for a fortnight but my son and his wife stayed for 6 weeks. They had saved their holidays up. They stayed with 'P's best man who they had kept in touch with and still keep in touch. They stayed with them. I didn't know the University let rooms for people on holiday like that. The four of them booked for the first fortnight into the University. (pause 2 seconds) They went into 'H's, their best man and stayed there for the other four weeks of their holidays. They hired a car and took me out to see the new Tyneside, Quay side which I hadn't seen. I didn't know anything about it. All the new flats and the gardens, it is lovely.

15

Everything seemed to be made of Sandstone, but it was really nice. My eyesight was going then. The doctor, the consultant gave me a kick in the stomach. After all of the test he said I am afraid you are one who slipped through the net and the only thing for you now is to register you blind. Well you know my stomach went down to my feet. What a way to put it. He could have been more gentle than that. The things went out of mind and I couldn't think of anything to say. I had a lump in my throat. You have slipped through the net, all we can do for you now is register you blind. Which he did and it has just got worse. It is funny. He diagnosed it as cataract, and a hole in the retina in the other. Other people in their 90's have had cataracts removed, can you not remove mine. No, there is a disease at the back of the eye. I have got a tape explaining it somewhere but I forgot what they called it. It is inoperable. When I look forward at a thing like that straight ahead I cannot see a ruddy thing. However, if I turn my head like that I can see the bird cage which is out of all proportion.....(inaudible discussion about her vision)

Deteriorating vision

16

No possibility of her eyesight improving

If it wasn't for these talking books that I get from the RNIB I would be crackers. I would be out of my mind. Cause I am not a good mixer. I'll tell you what happens. I used to go down to the sitting room which is beautifully decorated with lovely armchairs and lovely furnishings and photographs. Really nice you couldn't get it more homely. They keep changing things around which makes things worse for me. Never mind. They will introduce me to somebody and I can sit and talk with them for a little while, not very long. I can't always understand what they are saying. And the next day, I wheel myself straight pass them and they think, she's a bit stuck up there. And they don's speak to me and I don't speak to them (laughter) We are like bits of kids, oh dear God. To think that I have come to this. I have been talking to a woman for ages and the next day I wheel myself past her because I cannot see her and I don't recognize her. The girls I have to get used to their voices and recognize them by that or their outline if they stand still long enough. That is seldom, they are always so busy. They are so busy, that is one thing I would like to see an improvement made on - if, which I don't think will ever happen because they are always so busy. If they could only find time for only 10 or 15 minutes conversation per week to sit down and say I am here 'S' we can have a little natter. Just to sit and talk to somebody like I am talking to you, but this is nearly all about myself but I would like to hear them, what is happening outside. That is the only thing I would complain about. I don't complain because I know that that is impossible. The staff situation, they can't cope with that sort of thing, that's asking too much a one to one conversation. But even once a week would do, you know. I would not expect it everyday but apart from that it is great. They come dancing in at times and say "Are you alright 'A'" and I say "Yes". Why aren't you up and I say I do not feel like it. Right then you have a rest today. You know you can do what you want. They say, "oh you have your clothes on today" and I say" yes I am raring to go".

Activities are important

Visual problems contribute to difficulty communicating with other residents

Staff have little time to talk with residents

Sometimes we have entertainers, if S [the care home manager] can get a hold of them. The activity lady she is off. She has just taken the job over. She wasn't trained, she was going to start her training to be an activities person. She broke a bone in her hand and now she is on the sick. What with the weather that we have had, how some of them got into work I do not know. But they did. Some had to phone in sick when they had the flu. Some had a fall on the ice and they could not get in. Poor 'D' he

18

19

Knowing about the circumstances of the staff

comes from Alnick and he never missed a shift. He got stuck in Morpeth once when the snow was so bad.. (pause 3 seconds)

R What type of work did you do?

S Are we going right back. I was a gofor. Do you know what that is

R No I don't

S The youngest of the lot and it is go for this and go for that alright (laughter) Which meant that I left school at 14. I went to an ordinary elementary school. I didn't bother to try, we used to have matriculation, not O levels and A levels like they have now. I never bothered and I didn't try because I knew that they couldn't afford the expenses of the uniform and books and everything. So I left school at 14 and I got a job in Binns departmental store. I was the go-for in the gown department (laughter). The seniors you were terrified of them. You respected them, you practically bowed down to them, the authority they could issue. There was like me at the bottom of the ladder, all the rest up, there was the go-for and then there was the junior sales who did the packing. Then there was the senior juniors who were 19/20 to your 14. Then I got a slight promotion helping the buyer out as everything was on coupons in those days. The coupons had to be counted. You had to balance all of your coupons. It was 7 coupons for a dress, and 17 for a two piece, a dress and coat or a costume. A jacket and skirt were so many coupons and you used to have to take the ticket off with the selling price on and put it in one box and the coupons in the other. At night time you had to count up your coupons and count up your tickets. God help you if you were a coupon short. The go-for always got the blame - you have upset the box, you have upset the box. (laughter) 20

I stuck that for a while it was fun and I enjoyed it. When I got out on the floor to serve that was wonderful. My heart swelled with pride. I was serving the customer. You were trained how to speak to them, how not to get them to give you a yes or no answer. Like Can I help you - that was out because they could say no thank you and that would be it. You had to introduce them to your goods such as Isn't that pretty colour. When they are looking along the rails - you would say isn't that a pretty colour? They would say yes because you would pick the one they were handling as they were looking along and you would notice that she likes that colour. Then you would say that "I have got it in your size if you would like to try it on, and we have a fitting room just there for your convenience". "Thank you very much" they would say if they were nice. Some of them could be horrible. I must have been there for about 4 or 5 years (pause 3 seconds) because the war was on you see as well. I had been evacuated from Newcastle, Heaton to Wooler, near the border of Scotland. I was evacuated on the 1st Sept war broke out on the third and I was 14 on the 29th. So I was left school at 14 and I had to be sent home. That was the war. I left Binns. We had two nasty air raids. There was a land mine at the bottom of the street. A lot of people were killed with that. then they blew up the Goods stations, which was halfway between Heaton and Newcastle centre. They used to have food and everything on the ground. .....They put forms in the air raid shelters for people to sit on and the water was dripping down the walls. How people didn't die of pneumonia I will never know. They used to sit there all night when the raids were on. They were after the ships on the Tyne you see. (pause 4 seconds) I don't think they ever got one but they were quite close. New Bridge street was bombed. That was devastating. When people were walking to work the next morning you could see they had bombed the lines to the river. The electric tram cars and the line were bombed and of course you had to walk. You walked straight from the air raid shelters to work. Never mind that was the way the cookie crumbled in those days. 21

Then I went to work in a wholesale shop where they made the garments. JD Robbs on West Moreland Road. That was an increase in wages - not very much. There was less than shillings - there I am again ten shillings. Ten shillings is fifty pence isn't it. Aye. Well it was seven and six I got it was less than ten. It was a week you know not an hour. Ishh. Seven and six I worked for. And the first days pay at Binns, seven and six clutched to my hand. Oh I didn't have seven and six because I had off takes. I had what we used to call a big stamp and a little stamp. The little stamp was three-pence, and the big stamp was about nine I think. The little stamp covered you for accidents at work. You know and the other one covered you for six benefit and what have you. I have always paid the big stamp (slight pause 1 second). I had that taken off and whatever left out of seven and six. This is what I bought. I bought a quarter of butter brazils for my mum, a bar of chocolate for my sister. I bought ten Woodbines, that's cigarettes for my dad and a pair of stockings for myself. And I had to pay a weeks tram fair. I did all that on seven and six pence. You wouldn't credit would you. 22

R No

S You wouldn't credit it. How the hell we managed. Of course things were priced accordingly. We weren't paying four pound odd for a packet of cigarettes. Not even a new ten pence. We were conned when we went into the new metric money. My poor mother never got used to it yet. When I came back and told her that a bar of chocolate was ten pence she wouldn't believe it. We were using two ten shilling pieces for ten pence in those days when we converted into it. She used to hold out her hand for her change expecting change from a bar of chocolate and it was ten pence. She couldn't believe it. You have robbed me she said (laughter). I said I am not and she took to hiding her purse. It was everywhere in that house. She even put it in beside the clock at the back. Never mind. She missed the shelf one day, there was such a clatter. I said what's that and she said, nothing, nothing. I says you were doing something with that clock. It has never worked for years, but what are you doing. Oh you would have to find out, I was just hiding my purse. I said do you not trust me (laughter). Ah dear me. What a time we had getting money out of the clock. (pause 3 seconds) Crazy.

And then where did I go after that. Oh I went to Books fashions. My sister worked there she was first sales. She reached the dizzy heights of first sales. (pause 3 seconds) Oh dear. She could sell fridges to the Eskimos. She could she was a wonderful saleswoman. Wonderful. And of course in her day there was no superannuation. (pause 2 seconds) Lump sums we used to call them. There was none of those and all she got was a hundred pound when she left and she worked there for years and years and years. She must have made millions for them. Whereas I had supper-an when I left. That was the difference in nineteen years. (pause 5 seconds) Ah dear. I am going to have a cigarette and shut up. I have got myself a sore throat.

23

24

R I'll turn that off

S I have never talked so much

Appendix seven: Transcript of Anne's sixth interview

Story - Lines

Topics

Interview 6
Resident interview: A/6
25.4..01

keeping in contact with family

R So it was 'P' birthday (son)

S Yes. It will be over now, it will be 2 o'clock tomorrow morning. I hope he has had a nice day. He always has a holiday on his birthday because it is Anzac day (pause 2 seconds) .Australia and New Zealand Army Command, is the C for command

R it could be Corp

S Corp

R I really can't remember

S I am not sure myself actually. Never mind I did know. Another thing I have forgotten oh dear. Oh we have had a funny sort of week here. We had a flood in the kitchen. Poor June the cook she was demented. Everything had to come out including the cooker (……)

Staff Yes

S Can you take these dishes pet

Staff 'A' is going to come around with a tray - she is on her way up and she is going to collect all the dishes in from the rooms

2

S Okay. What was I saying pet

R That there was a flood in the kitchen??

knowing what is happening in the home

S Oh yes everything had to come out even the cooker had to come out. It had to be dismantled. All the floor cupboards had to come out and be dismantled. Emptied and bought out. They had to send to Greggs for pasties

R Oh they couldn't feed you

S They couldn't cook at all. You couldn't even get a cup of tea. Oh She was in an awful state bless her. I felt really sorry for her. Never mind as usual she coped and we had pasties and steak and kidney pies. You know whichever you wanted. that was one day. The carpet people lost a roll of carpet

R How can you loose a roll of carpet?

S Don't ask me that. I have visions of them folding it up and putting it in their pockets.

R Oh well when I saw them walking in it was a pretty hefty carpet to put in your pocket.

S You are not kidding. I shouldn't say it but I think that it has been someone on the inside. well it couldn't have got in and out without it being seen - it was £750.. Matron has also had her purse pinched. It has been a really traumatic week - everything has gone wrong. I don't no if I should have said all that!

3

R Well yes

S well I have. 'C,' the nurse who has switched over to night shift on Monday, she saw a lad running out. They got the police in of course and she has gone to the police station today to look at photographs and things to see if she can identify them. This young lad she saw run out - as he ran out he smashed the front door glass in the front door

R I saw that as I came in and I was wondering what was happening

S Well she thought that was him on his way out - he had broken it. Is it not mended yet?

R No there is a piece of wood over the front.

S Oh this was last week

R How did he get in

S Well if you no the number to get in you just press the number and the door opens

R But they don't give the number out freely

S Well all the relatives know the number

R But that is awful because if only relatives know the number it must be relatives

S Well yes, it leaves a nasty taste in your mouth it does really. I think it has been an inside job from their end. They had a van and they just dropped it off. They couldn't have got it in anybody's car. No, no way. Matron £30 and all her credit cards of course. But she had to stop them immediately and it will takes 4 - 7 days before she can get any money out.. There is one thing there is never a dull moment in this place. Do you remember what I was telling you about the group thing they were trying to set up. I forgot all about it and no-one reminded me. Did they? Not until it had started and matron came along and said are you not going to the meeting and I said what meeting. She reminded me on and I said "I forgot all about it 'E' and I can't be bothered it will already have started and I said if it is going to be just a complaints thing I am not interested." "They should have gone to you." There is no staff going to the meeting and that to me is just ridiculous. It is just going to put a wedge between the residents and the staff I think. That's my opinion it is just like going behind somebody's back isn't it. I said that to 'E' and I said oh no if they are not satisfied they should have come to you with their complaint. Not to discussion groups. That divides the staff from the residents - well D what do you think she has been saying about me. You know. It's only natural, only natural. However I haven't thought anything about the meeting. There is another one in about a month's time so 'E' is going to let me know what it is about.

R I thought they were going to talk to the matron at the end?

S Well I haven't seen matron today so I don't know if they did that or not.

R Ah right

S I don't know if she has got to know what it was about. But that was about 7.50pm when they were going out and matron had been on since 8am so whether she waited to see if she could have words with them I don't know. I wouldn't think so. I will see what the next meeting is about but they are dividing the staff from the residents and that's not the way to go about this job. You've got to get closer together not more distance between you. At least I think that.

R Why do you think that?

S Well I mean you are with them every day if they last long enough. Some of them are only here a fortnight. We have got another one leaving this week

R Oh who is that?

S 'N'.

R She has been here quite a while

S She is in today and she was in yesterday because she does the shampooing when the hairdresser comes in on a Tuesday. But they cut her hours so far back that she says it is not worth her while. She came as a cleaner and then she got to carer and she was trained as a carer and then the activities person

The robbery shook her sense of security - it was unsettling

How residents can influence what happens in the home (Making decisions 4

The importance of good relationships between staff & residents.

Staff / Resident relationships

The transience of staff influences how well staff residents know each other

5 Knowing about staff circumstances

left and she was given the job and said yes she would like to attempt it. right we will make the arrangements for some teaching where you get taught about how you go on about it training places. And I don't think she ever got to one and then she was poorly - she broke her hand, that was it. She was off and when she came back they cut her hours and said that it wasn't necessary. So we have got no activities going . Apart from we had an Easter bonnet parade on Monday and I don't think I have seen and Easter bonnet yet which was rather disappointing. Last years was beautiful. All the staff helped to make them you know

R Yes

S For the residents and they were sitting in their wheelchairs with their little hats on and there was prizes give. But this year there was not a hat in sight so what happened I don't know. But they had a raffle and guess the chicken name. I don't no who set the names but I got Butterbun. The name of a chicken. I have heard some names for things but never Butterbun

R No I haven't heard that one before

S No I haven't definitely haven't. Then there was a glass of wine and a buffet tea. There was a few relatives came but it was 3pm and that is not an easy time for relatives you know. Other times it is 6.30 and that is not an easy time for other relatives. You cannot win. There didn't seem to be a lot their last night. They had it in this top lounge. It is a lot smaller than the dining room where they had the last one

R Yes

S About half the size I would think. Sop what was discussed God knows. I think the staff and the relatives should try and get together and be friendly. And helpful. Well they are, some of them. Most of them are. 'N' told me on Sunday, no Monday. "S' I am leaving." I said "Oh you are not 'N'." She said "Oh I am". She says "The money is no good they have cut my hours." She is waiting for some benefit to come through but until she finds out how much it is going to be. But if she still leaves I don't know. But I think she still will because she is fed up

R Why is she fed up?

S I don't know. I don't think she gets on very well with the matron. I think that is the trouble because she keeps saying oh I wish 'S' will come back. Wish 'S' will come back and you can tell from words like that that she is not getting on so well with the new one. But you can't like everybody in the world can you pet.

R Too true

S Everybody has got their own likes and dislikes. (pause 3 seconds) So when they get the carpet laying finished I don't know

R Have they not finished

S No they have not finished the top corner up there

R I thought they had

S No up there

R Oh it is 'S' it is

S Eh

R OH no there is carpet bits all over

S That is what I thought but they said yesterday yes no bother but that is what they said last week

Limited activities in the home due to changes in staffing

Everyday / Casual or 6 annual events

Importance of staff & relatives to have good relationships

7

Why staff leave the home

8

R Big job

S Oh yes

S I think they have done upstairs. But as I told you it is terribly well I suspect it will be heavy to push your wheelchair

R Is it

S The pile is too thick, piles too thick. I don't know how the lasses manage 12 hour shifts pushing wheelchairs and trolleys back and forward I don't know how they mange because it must be heavy on their legs. I mean its not a flat faced pile like this one I mean there is pile. I managed to get down but I couldn't get back. I was exhausted so I had to wait until somebody was free to push me back

R How do you feel about it

S Well I have lost a little bit of independence again, haven't I? I am used to loosing a little bit every now and again. Now I have to ask somebody to push me back. Well before on the other carpet I could just wheel down and wheel back with about 5 minutes rest at the other end. I used to like to go down and collect any post like tapes and things that were down there for me in the mornings. And sometimes they are too busy to bring them up and I used to enjoy that because it was something that I could do for myself. But I can only mange one way. Never mind I will get used to it I suppose.

R Did you discuss it with them?

S Well I mentioned it and it was well God knows how long we have had the carpet on order because they have been talking about it for long enough. And I did say I hope that the pile is not too deep. they are experienced owners and they should know that sort of thing. wouldn't you think. You think they would know that. That is probably why they put that sort of thing in (pointing to the existing carpet) the last owners when it was built. They had known. If you go there and feel it

R Well I did when I was walking down

S Well there you see. well you try pushing a wheelchair. Oh dear I am grumbling again. What an old natter box I am getting.....I am just describing the way it is.

R That is not a grumble.

S That's it. that's nice of you to say that. (pause 3 seconds) Any more questions?

R well a couple here is the first one: In what situations do you seek contact with others in the home

S Well I don't think there are any. I never bother with anybody. I have always been on my own and I like being, I have always been a loner. Well I can't see them properly 'G.'

R Yes

S And I can have a little conversation in the foyer with me in the wheelchair and they walk past. Or they are in a wheelchair and they stop to have a little bit talk. Sometimes I can't understand what they are saying. I have got the ear phone going up and down like a yo-yo to get the sound. If they have got an accent I cannot understand them. Like we have had 3 colored people in this week cleaning and caring. Very nice friendly people but I couldn't understand a word they were saying. But if I see them again the next day I can't remember them, I can't recognize them by voice. I recognize the staff here by voice when they have been here a while you know. But if I just talk to them for a few minutes in the foyer when I have been down there I can meet them the next day I wouldn't connect who that was. So there is nothing I would communicate with them for...when I go down when we have an artist in and a singer or something like that. I just sit on my own and I can hear the singer. I can't see them. If she walked by and she had another dress on I wouldn't know her. So it is not worth the hassle because it only upsets me.

Becoming more dependant as a result of the physical environment of the home Loss of independence in another area of her life.

Endorsed expertise of staff

The physical environment of the home has a direct impact on a residents can and cannot do.

9

Visual problem has a direct impact on her interaction with staff

R Yes

S I would just listen to my stories. I have got a one there and it's not a very nice one. It has got a touch of cannibalism in it. I think I have read one his before. Can you tell me the name of the person?

R Rudolph Finette

S I must try and not get any more of them and it was all cannibals. Of course I never connected it with cannibalism and when I got half way through it I thought oh I feel sick. Cooking dead bodies and then they were eating them. then the heroin turned into a cannibalist. Is that the right word?

R Probably is.

S And she tasted it and she said oh it tasted like pork.

R Ah (laughing)

S Its getting back onto it. It starts off with badger catching tormenting the poor badgers. It is terrible. Unfortunately I have to listen to it because you can't turn forward on this machine

R Oh right so you have to painfully go through with it. Horrible,

S Yes. It will rewind but it will not go forward so you have to listen. But I am on to the second cassette now. 22 hours listening time which is good if it is a nice detective story. I like it then. Because I will have to listen to find out who is the guilty person.

R So are you intrigued now

S Yes

R You talked about contact with residents there but what about contact with staff

S Oh yes but not as much as I would like as I have told you before. They haven't got the time to come and sit and have a one to one. To have even a 10 minute conversation. They pop in for dishes and to bring you your food. Things like that. The hairdresser usually comes in before she goes and has a cigarette with me. That's nice, I like that. Only on a Tuesday. she is only in long enough to smoke her cigarette, about 10 minutes if that and that is nice. And here is one of my favorites.

Staff Well A was going to come up but she has come home for her dinner and I couldn't catch her could I?

S Oh you do the job pet

R Well you have been busy Are you out of breath.

Staff I am always out of breath.

S She has got asthma.

R Have you?

Staf Well yes.

S Don't take that it's my 2 pm time.

Staff I am just tired, I am really really worn out tired and my body needs a rest.

R You were tired last time weren't you?

Staff Well I have done 10 shifts off the belt.

Taking to have authority

10

Staff are too busy to chat but this is valued when they do

11

tracking the staff

S In 10 days.

Staff With no rest and I can't breathe and I will be coming in tomorrow to do 3 hours for them on a day which was supposed to be my days off.

S Oh dear.

Staff They are short of staff. One of the girls 'Y' has to go to take her baby to the doctors and she will be in at 11am. So I said oh well I will come in at 8 am.

S Long days pet.

Staff See you later.

S Goodbye pet.

R So its a short bit of time to collect the stuff and get out again.

S Yes.

R Do you still go down. when you went down to collect your post you used to have a chat with 'H' and 'S'?

S Only if I have business to discuss.

R So alright it wasn't conversation.

S Oh no. I mean they will if I go down and they shout come in. Well obviously you cannot open a door when you are pushing a wheelchair and they will open the door and say hello 'S' how are you la blab. Hold on a minute and I will see if there is any post for you and that's it and out I have to come. Its just not the time for them to sit and talk. But as I say it is not their fault. I dare say I could go and sit next door but the lady cannot talk and I can't understand her, what she says. 'L' over the road, the one who is always on the buzzer I don't understand a word of what she says'

R Is that her buzzer going off over there?

S Probably. she is always on the buzzer'

S Well I never have been one, neither has my family of being one who is running in and out of each others houses. I couldn't stand that. we would speak to each other and always be there to help each other if we needed it but not over the garden fence sort of style. We have never had that sort of relationship. I wouldn't have like it. I am a funny old buggar.

R We are all funny.

S I suppose so.

R We have all got our peculiarities.

S True, very true.

R Absolutely.

S You are making me talk about mine.

R But you agreed to talk about yours.

S That's right.

R I can't make you do anything.

S That's very true.

R What about situations where you actively avoid contacting people.

S Avoid them. I suppose by staying in here. I just stay and listen to my stories. That's avoiding everybody I suppose. That's all I do I don't get up and have a dance or p[arty. that's all I do to avoid people. I just stay where I am and I don't pester them and they don't pester me. That's the way I like it, I prefer it that way.

15 keeping to herself & remains in her room

R Do you just like people in the background?

S Yes, that's true. Then I have my friend on a Thursday night and she never fails bless her. That is always something to look forward to. We have got the same warped sense of humor.

16 keeping in contact with friends

R That is a situation where you actively encourage contact. There are other people relatives whom you have actively sought their company?

S Well they stand at the door and say hello and I will answer them. Naturally I don't ignore people. But they come to see their own relatives and not me. They haven't go much time either and they want to be with their own people and comfort them and not spend time with strangers .like me. They haven't the time either. There again some of them are not here long enough to get to know I suppose. There is a lady called 'A' and I haven't seen her for at least a week . I must ask how she is. She made friends with 'N' and it was lovely to see them walk past, hand in hand. And it was so nice and they used to call for each other and it lasted for about 6 months I would think. and then 'N' died and poor 'A' was absolutely lost she was devastated. I thought to myself I met her in the foyer one night when I was waiting for 'F' and she got onto talking about 'N'. She said "I am never ever going to do that again," and I said "What are you never going to do"? She said "Get friendly with anybody in here because they all die". Well I felt like saying that is what we are here for and this is the place to do it. She must understand that but I didn't want to upset her. She was devastated poor soul when she lost her friend. She has got it into her mind that everybody is against her now. I don't know why. She says I will not do that again and they can say what they like about me. I am not going to let in worry me. And that was the end of that cheerful conversation. (talk to the birds)

17 Transience of staff/residents

Pain of bereavement - death of resident

18 Loss and death are an integral part of life in the home

R If people were here for a long time would you be able to make relationships?

S It is possible I suppose but you never get that opportunity. You don't. Its either the staff you like they leave - they are never here 5 minutes.(stops to take medicine),

Transience of staff

R Just checking all my questions and you have covered them all. Is 'P' going to be here in a few weeks?

S 9th June he leaves

R He has still got it planned excellent. (inaudible conversation about 'P's journey and flights/directions) Is that the main line (referring to the train passing)? Does that disturb your sleep during the night?

19

Familiarity of the environment

S No it is funny I have always lived near a railway. There used to be one at the bottom of the street, about the length of this corridor. It never bothered me.

R Do you quite like hearing it in the background?

S Yes, reminds me of home I suppose.

R Do you ever think of this place as home 'S'?

S Now I call it home, yes. When they push you back in when you are going to the bus library

20

and I get all my books in carrier bags - they have got a lift which gets you into the bus. They have a thing that they push your chair on. I say thank you very much but I have to get back home now. I t just comes automatically now and yet if I talk about my own home I would say where I lived - my own home. I call this home now. Well after 6 years you have go to. Nearly 6 years anyway.

The care home as home - Place & space

R It becomes familiar then.

S Yes.

R Have you always had this room?

S Apart from the first 3 weeks. And then I had to go back into hospital and I was in number 4, when I came back this was empty. The old man must have died- he had been in hospital. And then I moved everything in. The matron we had then she was lovely, 'G', and she says as soon as number1 is empty you are going to have it. I said oh lovely because she had shown it to me. Then I was in hospital a month and when I came back all my things had been moved in and my own bed. Nobody else had slept on this bed in was brand new. It was a hospital bed. I had all my bits and pieces. It was like coming back into a home you know when I was seeing my own things. That was nice.

21 Importance of having personal possession in personal space

R Oh that is lovely isn't it.

S Yes.

R Why did you move down here. Did she think it was a better room for you?

S It was the biggest room in the place.

R Oh I see.

S Yes if you look in the other rooms you will find they are not as big as this. There is not a lot of difference you know. But it is this and number 20 and it was funny. 20 was empty when 'P' and my friend 'F' came around to have a look at it. They had been to a few and the social worker said that there was a new one in Forrest Hall that I would like you to see. She picked them up in the car and brought them in and of course as soon as they saw it all pristine, new and everything. It was lovely and this one and number 20 upstairs were this size. 'P' said that this was a nice big room. So 'G' said straight away that it will be 'S' if she wants it when she comes back. And he said oh that will be nice. So it was a toss up between this and 20. I moved into 20 because I lived in 20. She stood like that with her hand on the door and she said have you seen the number on the door 'S'. I said "No I didn't," and he said "Oh its 20, you win. Put her down for 20". However it was number 1 because it still wasn't full downstairs. Before they started filling up upstairs. And that was it and I have been here ever since.

Familiarity of the features of 22 the ho

Getting to know the home through others - helping her to make decisions

R Are you happy with this room?

S Oh yes. I would be very hard to please if I wasn't.

R You never come across that way. You always come across so easy going

S Good.I said to 'F' and 'P' to one house. You'll not know about that.

R No.

S Its down near the wall. You will not know of the wall?

R Oh I have been down there.

S Yes. Well that was a dilapidated state of a place. It was terrible. And they sent them to this home, not a nursing home it was just a house. there was a pub on that side and a pub on this side. And when you sent in the smell apparently had been so terrible it nearly made them sick. So 'P'hil said lets get out of here. My mum is not going to come in here. 'F' says "I wouldn't let here come in here". So they went back and played hell with the social worker that had sent her there. They said it was absolutely

See interview I

23 looking for a care home to move to

disgusting. Apparently it is still there. It used to be called Brinkburn St. No. It was on the left hand side in between these two. She said could you imagine them all coming out at night time. When the pubs empty. She said no way is she coming here. So they went on looking and came to 2/3/ places. But as I say this one, being new. Naturally they went for this one. I wasn't conscious that much when I first came in of what it was like. but when I had to go back into hospital. When I came back Matron bought me a tiny little cactus plant. welcome home it said on a little card from matron and staff.
That was a nice gesture. You see little things like that touch me. you know. Its just the little things that make it so bearable. That was a lovely gesture. And another thing. that touched me was. There is a red rose somewhere.

kind actn - important to Anne

24

R Yes there it is in a vase.

S Yes it is a paper one, plastic one. And we all got one of those on St Valentines day about 4 years ago I thought that was nice

R Was that the same matron?

S No she had left. She was here about a year and she got a home up at Alnick. And she wouldn't have left but we had a terrible winter with snow and ice, 4/5 years ago. She lived at Morpeth/ Rothbury which is beyond Morpeth. It was terrible driving conditions she had to go through. The length of the journey to get here and go home at night. she couldn't stick it any longer. She wasn't young. Well she was young compared to me. She got a nursing home in Alnick. I have heard from her since. She sends me a Christmas card every Christmas. That's nice as well isn't it?

knowing why staff leave

25

keeping i contact w staff at

26 leave the ho

R Is she the only one who has ever done that?

S Yes. And she is now area manager up there. So she will have left that home and goes to others that are up there. I don't know how many homes she has got. But that is what I have heard anyway. ?? Nice person 'G'. And then we got a chocolate egg at Easter. That was nice. It is little gestures like that that make it nice. They had a trip out to the Metro Centre.

kind actn are important

R Yes I came back last week to see 'G' because she went on that trip.

S That's right. They had enjoyed it apparently. I went to the first trip there during the first year I was here but I didn't like it. I didn't like it a bit. So when they asked if I wanted to go back I said no thank you.

having a choice in what she takes par in

27

R Nice to be given a choice though.

S Yes.

R Oh when I was looking for 'G' they said oh she has gone on the trip.

S That's right.

R Well it got to 3 o'clock and I thought that she would be too tired to talk with me. So I made an appointment to come back last week. There is no point if she is tired after being out all day.

S Oh no. I think they slept in the lounge when they came back. They all fell asleep.

R There is a large crowd in the lounge at the minute.

S Is there?

knowing abo the circums of other residents

R Yes I think there has been a lot more new folk.

S Yes. They come and go. I don't know if they have got the carpet down or not.

R I haven't been down that way.

S In the lounge. Have you seen 'E' today?

R I saw her as I came into the door. She popped out to let me in.

S I haven't seen her today. Not since last night when she was on about the meeting. Well that is all pet for today.

Appendix eight: Biographical data – the lived life and the move to care

The participant's life-story is presented in a chronological sequence to provide the reader with further details of the lives that these people lived prior to moving to a care home. The details differ. In some cases there is a lot of discussion of the career that they had and in other cases the discussion focused on what happened in their immediate family. There is no apology to be given for these differences. The stories are recorded in this way to remain true to the telling of the story as it was told in the interviews.

Anne

Anne, a 76 year old woman, had lived her entire life in one city in Northern England. She had one sister, who was 19 years older than her, and they were close friends throughout their life. Together they shared events and family responsibilities. Her sister helped her to raise her only son following the divorce that ended an unhappy marriage, and in later life they cared for their mother until she died at the grand age of 96.

Following school, at 14 years of age she entered the workforce as a "go for" in a large department store. Her career progressed through the posts of sales staff to the store buyer. This was a time in her life "when everything was going swell." She had made steady progress in her career and this was only impeded by ill-health. When she was 32 years old she had a laminectomy, and since that time has received intermittent treatment for various back problems. Eventually her back problems contributed to the decision to take early retirement due to ill health.

The retirement package funded a visit to her son and his family who were living in New Zealand. Her sister accompanied her on this journey. This was a particularly important visit because her 2 grandchildren were adults but they were still living at home. It was, therefore, one of the few opportunities where they could be together as an extended family. The sudden death of her sister during the visit cast a dark shadow over the time that should have been so happy.

Some years after her initial back problems she was diagnosed as suffering from arthritis in her spine, which caused chronic pain and led to progressively limited mobility. So far in the story Anne has managed to live alone in her large 5 bed-roomed house. Eventually her physical condition deteriorated to the point where she required continual support and care. She had various options for her long-term care. These included moving to New Zealand to live with her son, care in her own home that would be provided from community services or moving to a nursing home. She opted to move to a nursing home because she felt that it was wrong to be a burden to children and she didn't like the idea of strangers caring for her in her own home. She talks about this time in the following extract:

> "I was in and out of hospital and then back home. They (doctors) said I would need someone to look after me.....But they gave me the option of

having helpers at home. It was a 5 bed roomed up and down house that I lived in. It was a lovely home.....they suggested bringing the bed downstairs. I said what is the point in that? I said how am I going to get up the stairs to the bathroom? to the toilet? They said "Oh there would always be somebody there and they would work it in shifts." And I said, "what about getting in and out?" They said, "Oh we would give them a key."..... But I didn't want people walking in and out that I didn't know. I had an alarm put on and I thought they would be walking in and setting the alarm off. I didn't want that sort of home help and they suggested that I could move to a nursing home and this is where I moved to."

(interview 2)

So we know from her personal biography that she was actively involved in decisions about her long term care arrangements. This took place at a time when care in the community was being actively pursued in Governmental health and social care policies and professionals were being encouraged to involve older people in care management decisions.

Her son and a friend viewed many nursing homes - many they did not like. When they viewed the home that she now lives in, they described it to her and then she made the decision to move. At first she moved into room 20 (the same number as her own home). Three months later, room 1 became vacant and she requested a move into it because it was a larger room that was located on the ground floor at the back of the home. This room was adjacent to the metro line and she liked this because her home had been situated near a railway line. She has now lived in the home for 6 years.

Beatrice

Beatrice, an 86 year old woman, was the youngest of 8 children, and was the only surviving member of her immediate family. Her husband died 30 years ago. Although they wanted to have children, that never happened. In her later years she was saddened by this. She was brought up as a Quaker and she ascribed her childlessness as "God's will for her life." She had a large extended family and she described her nephews and nieces as close to her. They have maintained regular contact through their lives - one nephew visits every day.

Following her husband's death she continued with part-time shop work. This enabled her to continue to live in her bungalow. Although she described herself as 'not house proud' she paid great attention to the furnishings and the decor of her home. This gave her much joy. In her later years, she was unable to continue to maintain the property and decided to move to sheltered accommodation. The rooms in this accommodation were large enough for much of her furniture and she was able to organize it in a way that felt like home to her. With the move she acquired new neighbours and an extended network of acquaintances. She enjoyed taking part in the lively activity and entertainment program of the housing facility. Much of this was funded by monies that the occupants worked together to raise.

During a game of cards, one night, she had a stroke. Although she recovered

from this, she was left with residual problems. She had a left hemiplegia and was unable to move her left leg and arm. As she required assistance with most of her personal needs, she was assessed by health and social care professionals to determine the type and level of care that she needed. The outcome of this provided news that was both shocking and life changing for her. She was informed that she could no longer live in a place that did not provide nursing care and she would move to one that did. The nursing home that was chosen for her by her family was only a short distance from the sheltered housing complex. It may have been a larger distance because she no longer saw any of the other tenants of the housing facility.

She described her latter years as a time of loss - loss of family, friends, home and abilities:

> "The last years have been very dramatic really, they have been hard years. I have lost my brother and mother and husband and everything and my house. I have got no house now, I have got nowhere to go to, you know if I wanted to. I couldn't come up here (to her room) unless I got in the wheel chair and then I would have to get a nurse or a carer to bring me up and put me on the bed and then she would go away.....All of it happened after the stroke. I was doing everything myself before the stroke, washing and ironing, going messages and all the gardening and everything." (interview 1)

She has now lived on the ground floor of the nursing home for 2 years.

Charles

Charles, a 88 year old bachelor, was the oldest of 5 children. One brother and one sister remains alive and he has regular contact with them. He is very positive about his life and he feels that he has been very fortunate. His memories of his early childhood were warm - his mother and father were always there providing everything that he needed and he had good friends to enjoy a carefree existence with. Apart from the time in the army, when he worked abroad, he had always lived and worked in the same locality. As a consequence he felt that he was a part of the local community.

After school he entered an apprenticeship as a barber. This was not an active choice, but he felt that he was always in the "*right place at the right time. In this way things always worked out well.*" Following his apprenticeship he set up his own barber business in the parlour of his family home. Apart from a short diversion in the Royal Corps of Signals he pursued this career throughout his life. It was only when he developed visual problems (through a detached retina) that he had to consider alternative employment. This led to him working for a short time from 61 to retirement as a forecourt attendant - one of the few occupations that he didn't joy.

Through work and his many personal interests, such as cycling, walking and golf, he developed life-long friendships. He values these friendships greatly and continues to enjoy meeting with the same people weekly following his move to the care home.

He lived independently in the family home until he had his left leg amputated. Following this he was offered the support of community services to enable him to continue to live at home. He declined this, because he felt that he would not be able to manage adequately and he wanted to make the move to a home at the point he could influence what was happening to him. He recalls his decision to move to the home where he has now lived in for 6 years in the following way:

"well with me being short of eye sight it was obvious that I wasn't going to manage very well. And I thought that if I was going to go into a home I wanted it to be in this one. I wanted to be in here and it just so happened at that particular time that this room must have become vacant and I was in. I didn't realize how lucky I was to be in here because it was so handy for everyone - well all of the people who visit me. It is so handy for them...well my sister gets the bus right to the door, it couldn't be any more handier than that...and apart from that I don't think that there will be a better home. I couldn't imagine what could be a better home." (interview 3)

Doris

Doris, an 84 year old woman, had seen many hard times throughout her life. She was the youngest of 8 children and many of her siblings did not survive childhood. Although she was the only surviving member of her immediate family, she maintained contact with her nephews and nieces. One nephew, who had always been a great support, continues to visit her regularly since she moved to the home.

Following school she spent a few years working in her home to support her mother and it was only when women were needed in the labour market that her parents allowed her to enter paid work. Her first job was in an armaments factory and she worked there for 9 years. This was heavy grinding work, where the female workers were fearful of the managers. Following this she became a "*well-sought after*" barmaid. This was when she met her husband.

She was 28 when she married and he was a lot older - 58. Her marriage was a disappointment, and she said that is "*was a mistake.*" Shortly after getting married he became ill and she nursed him until he died. From then onwards she lived alone. She devoted her time to maintaining her home and enjoying the company of her friends.

As her age advanced she was supported to live independently in her own home by her nephew. This was very important and enabled her to live a satisfying life. She recalled vividly the time when she went to answer the phone in the hallway and she collapsed. She crawled over to the door to take the lock off and she called to neighbours who couldn't hear her. At this point she remembered that she lay down on her own. She thought *"there is nothing for it but to lie because I could not move, I couldn't pull myself up. I thought oh my God this is it."* After 3 days a neighbour found her and she was admitted to hospital. She went through rehabilitation following the stroke and regained the ability to walk. But, she was left with residual problems and was unable to

self-care.

She agreed that she would not be able to live alone in her own home, and with the assistance of her nephew selected the home that she now lives in. Initially she moved to the home for a trial. Following the trial she decided to stay and has now lived there for 1.5 years.

Edna
Edna, an 83-year-old woman, had led a full and active adult life that she described as "a whirlwind". In her twenties she moved to London from the North and lived with a cousin in Ascot. They had an exciting time, and enjoyed the parties held in the higher echelons of society. On one occasion she recalled meeting the Queen mother and the Prince of Wales.

Following this time she had a short and unhappy marriage. She divorced and went to live with an aunt in Africa for 6 months. Her father advised her to do this - to reflect on her circumstances and to make decisions about her future.

When she returned to England, she joined the WRAF as an officer and spent most of the war years in Egypt. Illness prevented her from continuing to serve in Egypt and she returned to England where she secured a position as a secretary in a private girls school in Harrogate. She remained in Yorkshire until her father's health deteriorated, then she returned to Newcastle to assist her mother to nurse him.

Following her father's death, she returned to work in Newcastle in the records department of an NHS hospital. This was a demanding time in her life, as she coped with caring for her aging mother, setting up a new home and meeting the requirements of her job. Although she was the main carer for her mother, her brother lived nearby and he was a great support. Together they looked after their mother in her own home until her death.

When Edna retired she remained in Newcastle.. When she felt that she could no longer live in her own home she moved to a sheltered housing. Whilst she required some support with shopping and housework, she was fiercely independent. She became friends with others who were living in the complex and her life revolved around the social evenings when they enjoyed a game of bridge or a movie. It was only when she had an amputation of her right leg that she faced the decision to move to a place that provided accommodation and care. She knew of a home within Newcastle that had a good reputation and she wanted to move there. Her brother and her sister-in-law visited the home and they found that there was a vacancy that she could apply for:

"I came here, Well I knew all my friends. Well I was in the hospital and I knew this place. So I just came and I knew a lot of friends. I say my brother tried this and found that it was very nice. I think that it was suitable for me anyway. I chose to come in here – it is very nice." (interview 1)

She had always had a close relationship with her brother and after he and his wife helped her to move to the home they continued to visit her 3/4 times per

week. Her brother has been very unwell during the last year and is now waiting for elective surgery. She is worried about him, and feels frustrated that she is unable to support him in the same way that he had done for her. Now, they keep in contact through telephone calls.

After moving to the home she had a stroke. The stroke left her quite incapacitated – in addition to the mobility problems that she already had, she now had minimal movement of her right arm. She also experienced expressive aphasia, which resulted in difficulty communicating with other people. Now her main anxiety was the chronic infection of her left foot. This worried her. It might lead to a situation where her remaining leg was amputated. She feared the possibility of this happening and spoke of this quite openly, for example she stated - "*oh I hope they don't start chopping off other parts of my body, I would rather die than let that happen.* " (interview 2)

Whilst she acknowledged the pain and discomfort associated with this, she feared the increased dependence that this would bring. She has now lived in the home for 4 years.

Florence
Florence was a 95 year old, single woman. She was the youngest of 4 children and was the only surviving member of her close family. She had fond memories of her childhood, describing it as "*a carefree and happy existence".* She lived in the countryside and in that setting life revolved around the family, doing things together and looking after each other.

During her early adult life, she joined the WAF as a short hand typist for the Churchill Office. These were frightening, yet exciting times. There was great camaraderie in the team of 6 women that she worked with and they became very close friends as a result of the difficulties that they shared during the war years. Their work led them to travel together and they continued to do this for pleasure rather than business after the war.

There were some gaps in her story and it is unclear when her father's health deteriorated. When this happened she returned home to nurse him until he died, and later did the same for her mother. Following this difficult time, she moved to her friend's home in Newcastle and lived with her for 26 years. They pursued the arts with enthusiasm, enjoying a quiet but satisfying life. Few people understood the closeness of their relationship and the taboos in society of any type of relationship other than a heterosexual one prevented open discussion of her partnership. It was with great sadness that she nursed her friend until the final stages of her illness. When she could no longer care for her, she moved to a nursing home. Neither women liked the move to care nor the home, however, they felt that there was little that they could do to change these circumstances. When she died, a friendship that had existed for half a century ended.

Although Florence continued to live in the same home following her friend's death her life changed and she felt unable to experience the pleasures that she had enjoyed for so long.

When she was 93 she had a stroke. She was alone in the flat, and had enough awareness to crawl to the door and open it. A neighbour, who was passing by, summoned help. She survived the initial impact of the stroke but was left with disabilities. She was no longer able to walk and her eyesight had deteriorated to the point that she had little vision. The professionals suggested that she might consider a move to care. Prior to the stroke, she had experienced difficulty in managing her home, and now she was unable to do more things for herself. Her relatives lived in the south part of the country and the distance prevented them from providing any more support than regular telephone calls.

She agreed to move to a nursing home. She asked the care manager to make inquiries about a nursing home that a neighbour and friends had moved to:

I had no choice of home. This was the best home in the area.
Researcher: *How did you know that?*
Well I knew that from past experience. Other people, my friends had been here…. Oh I had visited friends so I knew a bit what it was like. And this was the only place that could take me as it was just before Christmas so I came here and I have been here ever since. (interview)

There was one unoccupied room on the ground floor, which she was offered and she` accepted it. She has now lived there for 2.5 years

Gloria
Gloria, a 73 year old woman, was the youngest of 4 children. One brother remains alive but the remainder of her family have passed away. She was 18 years his junior and as children they were very close. Throughout her life he continued to have frequent contact with her and was a great support.

She had been a very attractive young woman who had taken pride in her personal appearance. She had kept her blonde hair always neatly arranged and she wore little make-up because she had a good complexion. Clothes were her greatest joy. When she shopped she always bought items that were of the finest quality and made every effort to co-coordinate her wardrobe with matching accessories.

Her earlier life was devoted to caring for her husband. Her days were filled with the routines of preparing meals, cleaning and maintaining the house. She was "*very house proud, too house proud really,"* and she achieved this through regular routines that commenced early in the morning until late at night:

> *I was always going out and washing my window sills down, my front door and steps down. And that was all before 8.00am in the morning. He (*husband) *used to say oh you like work don't you and then I would go to the shops and get what I wanted and then come home and bring it in and cook. Then I would stand and do the*

ironing. I was house proud too house proud really.(interview 1)

I like to be doing something. In the house I liked to have something to do, I didn't like sitting around. (interview 2)

Her latter years were dominated by chronic ill-health. Her problems started with arthritis. From this disease she experienced constant inflammation of her joints, which caused her much pain. Most of the time she coped with this but sometimes the chronic pain prompted her entry into a deep depression. On 2 occasions a psychiatrist treated her for this. Whilst this helped to change the way that she felt about her life the assistance did not remove the pain that caused the mood change. Her condition continued to decline and in her forties she had extensive problems with her movement and her speech. This was attributed to arthritis at first, and later diagnosed as Parkinson's disease. As a consequence of these diseases her physical and mental state progressively declined:

I can't walk I can't stand up you see. I have got no sense of balance you see and that is what causes me to fall. When I was younger I was always rushing about you see. But I have slowly deteriorated with the Parkinson's disease.(interview 2)

Her marriage slowly changed. She had once been the homemaker, then she became the cared for partner as her abilities deteriorated. Her husband was loving and he attempted to meet all of her needs in a very understanding way. They led a quiet life, anticipating that their time together was limited. Some time after living this way, he became ill with cardiac problems. He agreed to have cardiac surgery, which he did not survive it. She had outlived him and this was totally unexpected.

This was a time of so much death in her life. Not only had she experienced the loss of family and close friends, now her husband, her carer had died. With no support at home, she faced the decision to move into care and this brought further losses. When she spoke of this time tears trickled down her face. She *"never thought that I would end up like this."* From her story it is unclear how the decision was made to move to the home that she has now lived in for 6 years.

Since moving to the home her physical condition continued to decline. She is now unable to do most things for herself. When she is able to speak her voice is barely audible. Her ability to move varies - some days are better than others. Most of the time her limb movements are jerky and uncontrollable so she can only walk with assistance. In addition to all of these problems the pain that she has lived with for so long continues. Now she often thinks of her own death and the release that it will bring.

Harriet

Harriet, an 80 year old woman, was the second of 3 children. Their mother was a dominant woman who made the decisions that shaped their lives. She dictated what they could do when they were children and chose their careers

when they were adults. Harriet could only recall a few occasions when they attempted to challenge her authority. Though they supported each other during these times they usually failed to overturn their mother's decision. She was a formidable woman, sometimes viewed as a "tyrant" by the girls. There was little mention of her father throughout her stories so we do not learn about him.

Harriet's early teenage years were marred by illness. She was most acutely ill with meningitis, which left her debilitated. Her main long-term problem from this was the spasticity of her lower limbs. Some time later she had an operation in an attempt to increase the muscle length to enable her to walk without a limp but this was unsuccessful.

Though their careers led them in different directions, the sisters remained close friends throughout their lives. Her oldest sister trained to be a teacher and the youngest became a seamstress. Harriet was given no choice. She had a duty to fulfil and she did this by working with her parents in the family store. She felt that her sisters were supported to develop their careers whereas she had few opportunities to do the same.

"But in those days you didn't count the time, you just worked on and on and on. As though it was your duty. Because my sister went to College. She went to be a teacher. She has travelled all over the world teaching.....I was in the background all the time working in the shop." (interview 1)

In her late twenties she rejected her mother's idea that she would remain at home and decided to accept the marriage proposal from the man that she loved. After her marriage she continued to work in the family shop and developed a rich social life as a "*church goer.*" She took part in everything from the church services to assisting with the Girls Brigade. Her husband participated in the men's institute and met with other men there to play billiards. It saddens her that she has been unable to continue to participate in the life of the church in her later years.

When her mother decided to close the shop to fund her retirement and relocation to a nearby seaside village, Harriet had no work. Her husband urged her to retire. She did this and enjoyed spending more time with him. Following his death, Harriet moved in with her mother and her eldest sister.

When her mother died Harriet continued to live in the house with her sister who provided the care that she needed. It is not clear from her story when she had the stroke that left her immobile and unable to move her right arm. What we do know is that Harriet required more and more care as the years moved on and her sister experienced difficulty in providing this:

"my sister said that she was getting too old to look after me. Of course she is 80 gone." (interview 4)

In addition to her other problems Harriet began to fall. When she fell in front of the living room fire and sustained severe burns her sisters suggested that she

should move to care. They found a care home with a vacancy and Harriet agreed to go there. She believed that this was a temporary placement for rehabilitation. She has now lived in the home for 3 years.

Since moving to the home she dreams of moving to a place of her own again. She knows that other people feel that she would be unable to cope by herself and she would be unable to make such a move without their support. She does not agree with her sisters and the professionals and she feels that her views are disregarded and she has been rejected:

"when folks get old they don't want you, you see you are a case off on the rubbish heap. Well that is how I feel." (interview 5)

Appendix nine: Conference papers, articles and book chapters arising from this thesis

Cook (2001) *Nursing homes are communities: an exploration of the experience of group living in later life.* Bridging the gap: Furthering understandings of older generations and exploring partnerships – 5th European Nursing Older People Conference. 6th Nov 2001.

Reed, J.; Cook, G. & Burridge, C. (2002) Loss and change. in Hockley, J. & Clarke, D. *Palliative care for older people in care homes.* Buckinghamshire, Philadelphia: Open University Press, pp. 52-65.

Cook (2003) *Creating personal life space in a nursing home: the experiences of older residents.* Unsettling the ordinary – changing ideas about ageing, British Society of Gerontology Conference. Newcastle upon Tyne 4 – 6 Sept 2003.

Reed, J.; Cook, G. & Cook, M. (2004) Research governance issues in the care home sector. *Nursing Times Research*, I9(6), pp. 430-439.

Cook (2005) *Alive or living.* National Care Home Research and Development Forum, Newcastle upon Tyne. 17th June 2005.

Cook (2006) *Settling in : what is important to residents in their new home.* ESRC Research Seminar Series 2005/6 Transitions in Care Homes: meeting the demands of the 21st century. 27th Jan 2006.

Cook (2006) *Living with care rather than as an object of care.* Working with older people RRG and Northern Ireland Reminiscence network. 3rd April 2006.

Cook, G (2006) The risk to enduring relationships following the move to a care home,' *International Journal of Older People Nursing,*1(3), pp 182-185

Cook, G; Brown-Wilson, C & Forte, D. (2206) The impact of sensory impairment on social interaction between residents in care homes, *International Journal of Older People Nursing*, 1, (4), pp 216 - 224

ORIGINAL ARTICLE

The impact of sensory impairment on social interaction between residents in care homes

Glenda Cook MA, RGN, RNT
Principal Lecturer, Northumbria University, Newcastle upon Tyne, UK

Christine Brown-Wilson RM, RGN
Lecturer, Sheffield University, Sheffield, UK

Denise Forte MSc, RGN, RSCN
Principal Lecturer, Kingston University & St George's Hospital, University of London, London, UK

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Correspondence:
Glenda Cook
Principal Lecturer
Room H017
Coach Lane Campus East
Northumbria University
Newcastle upon Tyne NE77XA
UK
Telephone: 0191 2156117
E-mail: glenda.cook@unn.ac.uk

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The impact of sensory impairment on social interaction between residents in care homes

Aim. The aim was to draw on older people's narratives to illuminate the experience of living in a care home and the impact that vision and hearing impairments have on the individual's ability to engage in social interactions with other residents.

Methods. The paper draws on two research studies, first, a hermeneutic inquiry examining the meaning ascribed to living in a care home, the second, a constructivist study, exploring relationships between residents, families and staff. Both studies drew on older people's narrative accounts to explore their experiences of living in a care home. On independently interpreting the narratives a similar theme emerged around the challenges to social interactions experienced by residents with sight and/or hearing impairment. This resulted in a cross study analysis to further illuminate this theme.

Findings. The cross study analysis highlighted the difficulties residents experience in interacting with others, in the home, as a consequence of sight and/or hearing impairment, and the potential impact this had on feelings of social isolation. This is illustrated through narratives from two residents, one with sight impairment and the other with hearing loss. The narratives highlight the problems these people encountered and how resilient they were in adjusting to their sensory loss and maintaining social interactions. One conclusion from the study is the need for more empirical work in this area.

Relevance to clinical practice. The paper identifies a number of issues for practice including staff taking a more proactive role in screening for, and managing, visual and hearing impairments in residents. Also the vital role staff play in ensuring the environment optimizes the residents' ability to fully engage in the residential community.

Key words: care homes, friendships, narratives, relationships, residents, sensory impairments

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Background

Older people move to a care home when they are no longer able to live independently in the community. In the UK, care homes are facilities that provide personal, nursing and social care in a residential environment. The move to a care home, therefore involves relocation to a new environment and a change in living arrangements. In this setting the older person is in close continuous contact with other people who require care and support with their daily activities. They may share few or no common interests with these people other than their need for assistance. Together these factors have a significant impact on the type and quality of social relationships that residents experience.

When conducting studies concerning residents' experience of living in care homes the authors observed that sensory impairment(s) had a major influence on the lives of older people, particularly with reference to their interaction with fellow residents. These ideas were reinforced during discussions of the preliminary analysis of their respective studies during meetings of the National Care Home Research and Development Forum (see Cook, 2005 for a discussion of the Forum). This prompted the authors to revisit their data to undertake a cross-study analysis of the way that sensory impairment impacted on how participants interacted with other residents on moving permanently to a care home. This decision was also influenced by knowledge of earlier studies by Retinas and Garrity (1985), Resnick *et al.* (1997) and Wallhagen *et al.* (2001) that pointed to the significant influence that sensory impairment has on older peoples' sociability, social engagement and quality of life in care homes.

The purpose of this paper was to add to this literature by focusing on what can be learnt from residents' narratives of the difficulties that they encounter in interacting with other residents when living with sensory impairment. This paper will also explore how staff can promote the development of practices that support residents in interacting with fellow residents, which has the potential to lead on to meaningful relationships between residents.

Review of the literature

Within the gerontological literature social engagement is identified as having an important influence on self-perceived quality of life, life satisfaction, self-esteem, well-being, continued functioning and health in later life (e.g. Hooyman, 1983; Lee & Ishii-Kuntz, 1987; Traupmann *et al.*, 1992; Farquhar, 1995; Bowling *et al.*, 2002). Indeed, international studies have identified the value older people place on social interaction and developing relationships with other residents (Mattiasson & Andersson, 1997; Relatives Association, 1997; Raynes, 1998; Eales *et al.*, 2001; Kane, 2003; Hubbard *et al.*, 2004). Mattiasson and Andersson (1997), for example, found that the majority of older people residing permanently in nursing homes in Sweden, wanted to engage in social relationships with fellow residents. However, many of the participants found this aspect of their lives unsatisfactory. These findings echo the evidence that older people experience low levels of social interaction in institutional settings with much of their time being spent in social isolation (MacDonald *et al.*, 1985; Bowie & Mountain, 1993; McKee *et al.*, 1999).

There is increasing evidence that older people actively seek ways of interacting and relating to fellow residents, but this is not without its problems (Savishinsky, 1991; Grau & Wellin, 1992; Reed & Payton, 1996; Fiveash, 1998; Raynes, 1998; Reed *et al.*, 1999; Hubbard *et al.*, 2004). Hearing and visual impairments, speech problems and diminished cognitive ability restrict interaction between residents. Mobility problems limit the possibility for residents to move independently in a care home, thereby decreasing opportunities for chance encounters between residents when they may identify common interests (e.g. Retinas & Garrity, 1985; Mor *et al.*, 1995; Kovach & Robinson, 1996). Largely missing from this literature are detailed accounts of the older person's perspective of the impact of sensory impairment on the subtleties of interaction and developing relationships between residents.

Though there is little scientific evidence on the extent of sensory impairment in the care home population, there is evidence that visual impairment and hearing loss are major health problems in older people (Keller *et al.*, 2001; Yueh *et al.*, 2003). Estimates of vision impairment at ages 75–84 range 7–16%, and at ages 85+, 24–38% (Tate *et al.*, 2006), and 71% of the over 70 age group experience hearing loss (Royal National Institute for Deaf and Hard of Hearing People: RNID, 2006). These statistics have major implications for the care home population as the prevalence of entry to care homes increases with age (Age Concern, 2004). Indeed, Mitchell *et al.* (1997) found that visual impairment and blindness was a factor that contributed to an older person requiring a placement in a care home.

Sensory problems vary from minimal impairments to major sight loss and hearing impairment. Even mild hearing impairment has been shown to have a major impact on the social functioning of older people with increased reports of isolation, and loneliness (Wallhagen *et al.*, 2001). In frail older people, hearing impairment is associated with a decrease in functioning in instrumental activities of daily living, and reduced social engagement, which may contribute to a reduced quality of life (Keller *et al.*, 1999; Dalton *et al.*,

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2003). Similarly, visual impairment is recognized as having a significant effect upon the quality of life of residents (Dargent-Molina *et al.*, 1996; Lee *et al.*, 1997; Llewellyn-Jones & Baikie, 1997). The effects of visual impairment include depression, social isolation, loneliness, increased incidence of falls, increased risk of accidents and decreased ability to perform basic activities of living (Retinas & Garrity, 1985; Marx *et al.*, 1992; Llewellyn-Jones & Baikie, 1997; Resnick *et al.*, 1997).

Sensory impairment, therefore, has been found to have a profound impact on the way that older people interact with others, which can be problematic to them and potentially distressing to the people that they live with (Tolson *et al.*, 2002). This paper adds to this knowledge by examining the ways residents with sensory impairment report they interact with fellow residents in care homes.

Methods

This paper reports on two studies (Study A: G. Cook; Study B: C. Brown-Wilson) that were undertaken independently. Whilst these studies adopted different methodologies, both drew on older people's narrative accounts to explore their experiences of living in a care home. The method for each study is briefly outlined. This is followed by discussion of the secondary analysis of the data from both studies, which resulted in the findings that are presented here.

Study A

This was a hermeneutic inquiry that sought to investigate the meanings that older people attributed to their experiences of living in a care home. The research was inspired by the writings of Gadamer (1975) whereby understanding is considered to arise through a dialogue between the researched and the researcher. The research design explicitly aimed to facilitate frail older people to tell stories of their life as a resident. Narration, through a series of episodic interviews, was adopted as the data collection method in the inquiry to achieve this (F. Schutze, University of Bielfeld, Germany, unpublished manuscript; Flick, 1998).

The sequence of up to eight interviews commenced with a life history interview. The subsequent interviews began an account of life since the previous interview and then focused on a specific issue about living in a care home, such as the experience of living with others. The final interview was a structured discussion about the dominant narratives that had been identified through open coding of the preceding interviews. This facilitated on-going dialogue between the informant and researcher and development of understanding of the experience of living in a care home from the standpoint of the participants.

Eight older people, aged between 52 and 95 years, who had lived in four different care homes between 1.5 and 6 years, were invited to participate in the study during a 6-month period. In line with Local Research Ethics Committee approval, the participants were fully informed of the nature of the study and what would be required of them. In addition, informed consent was revisited at the beginning of each interview. In total 53 interviews were carried out (as the interviews progressed, the length of the interview sequence was reduced if the older person indicated that they had no further stories to tell).

Study B

Resident's stories in this study, were derived from a constructivist study (Guba & Lincoln, 1989) that explored relationships within three care homes from the perspective of residents, their families and staff. Constructivism contends that there are multiple perspectives and aims to develop shared meanings between participants, including the researcher (Rodwell, 1998).

The findings presented in this paper relate to the narratives of 18 residents (aged 70–100 years) who lived in one of the care homes within this study. Data in this home was collected through six semi-structured interviews with residents, 100 hours of participant observation and two resident focus group interviews. The researcher attended the home on different days at different times over a 9-month period. These days and times were mutually negotiated with all participants, following a process of informed consent, as identified in Local Research Ethics approval. Opportunities to speak with residents were negotiated on the day the visit took place to enable all participants to be involved or not depending on their health and well-being.

During conversations, residents involved in this study described how their past lives influenced the relationships they developed within the care home, particularly with other residents. It was through these narratives, that the experience of living with sensory impairment and supporting other residents emerged.

Analytical framework

Both studies utilized an interpretative framework for the analysis of the participants stories of life as a resident. These frameworks developed from a dialectic movement between the whole and the parts of the interviews as the researchers shifted between the stories that the residents told to examine

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what their stories were about. As both researchers independently developed a deeper understanding of these stories through critical in-depth interpretation, it was identified that older people with sensory impairment faced particular challenges, such as being misunderstood, when interacting with fellow residents. During a discussion of these preliminary findings both researchers realized that they were moving towards a similar interpretation and agreed to revisit their data to examine the features of stories about interaction between residents.

The secondary analysis addressed the questions: How does sensory impairment influence the way that residents interact with each other? What are the difficulties and/or tensions that older people with sensory impairment experience in their interactions with fellow residents? The codes that were derived from this process were discussed during a second meeting. As the discussion focused on exploring the codes, rather than original data, which each researcher had generated from their own data, the process remained within the parameters of the original informed consent. In addition pseudonyms were utilized throughout the secondary analysis to maintain the participants' anonymity. This discussion led to review and refinement of the codes, and through continuing dialogue between the researchers three themes were developed: 'Being a member of the resident community'; 'Getting to know other residents and supporting each other'; and 'Maintaining interaction and developing relationships with fellow residents'. These themes were then verified by a colleague who had not been involved in either study.

Findings

A number of issues emerged from both studies including the impact of environment and sensory impairment on the ease or difficulty of interacting with fellow residents and developing relationships with them.

Being a member of the resident community

Being with other people is an inherent part of living in a care home. From the privacy of their rooms older people can hear about the lives of their fellow residents. One person described the way that she became familiar with other people in the home:

> They are in the background, you hear about their relatives and you listen to their conversations, when they are walking up and down – they are just acquaintances. (Resident, study A)

Being able to hear conversations between other people that occur within the social milieu of a care home is important to residents, as these enable them to feel that they are part of a living world, rather than living in sterile isolation. These conversations are an indirect source of information that provides background information about other residents that they meet through the activities of daily life in the care home. Residents who have limited hearing are disadvantaged in the sense that they are not privy to this information, and in the way that they live with background noise that is distorted hence providing little meaningful information about what is happening in the home.

Whilst it can be comforting to know that other people are present in the immediate vicinity, this can also be viewed as an unwanted intrusion into their lives. The noise nuisance from multiple televisions channels playing at once, for instance, can be a source of irritation as highlighted by this resident:

> I switch off (her hearing aid) sometimes when there's about 3 different channels on the televisions going on (in the adjacent rooms). And each one (other residents) is turning it (their television) up higher to hear theirs. And the next one goes higher again and I think I might as well just switch this off – I can't hear a damn thing even with the hearing aid in. (Resident, study A)

In the main older people enjoyed the companionship that they experienced in the care home. In some cases their interaction with other residents developed into friendships as described in the following quotations:

> When I came here, at first I met Mary We had a chat. I didn't know her at all. And we became very good friends. (Resident, study A)

> There were 2 ladies and she made friends with a lady called Nora on this side. They were sweet to see together because they used to walk up and down to have their constitutional. Ann used to say come on Nora get yourself pulled together and we will go for a walk and they used to walk up to the lounge... That was their daily routine. They used to do it once in the morning and once in the afternoon. (Resident, study A)

Through their exchanges with each other, residents identify those who have had similar previous experiences to themselves and people who share their interests. Constant exposure to these people can lead to an incremental development in their relationship. In addition to providing evidence that residents develop close relationships with each other, the narratives pointed to the way residents with sensory impairments required support in their interactions with other people. The participants spoke of their difficulties in establishing and maintaining their interaction with fellow residents so these themes are explored in the following sections through the discussion of two narratives.

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Getting to know other residents and supporting each other

The first narrative emerged from stories retold, during study B, by three women who met following their move to the care home. Every morning the care home staff assisted them to go down to the communal lounge at a certain time where they sat in the same positions near to each other. They spent the majority of their day in the lounge, talking together. One member of this group, Gwen, had visual and hearing impairments. From her perspective, it was important to be near people that she could hear as this enabled her to be involved in conversations:

'There are two people I sit near and I can hear to talk with, everyone else is so far away. I would be lost without them. I can talk to Freda because I can hear her. She keeps me up to date, I usually have to ask her what's for dinner. There can be somebody next door to Freda and I just can't hear them. I should feel lost if there wasn't the three of us. If Betty and Freda weren't here, I would be lost. (Residents, study B)'

Through their dialogue these residents became aware of the common interests they had shared that provided a point of contact in their life histories from which their interaction developed based on mutual understanding:

Well it was that I just happened to sit there, near her and she said 'You're the only one I can hear,' and she kept saying is 'Freda down yet?' And if I was down first, I could hear her coming along the corridor... that's because she said she could hear me. In the course of talking of course it came out that we were both teachers. (Resident, study B)

As a small group these women accommodated each other's problems. This facilitated their interaction with each other, creating the conditions whereby they became more familiar with one another and comfortable in each other's presence. An implicit feature of their interaction was their empathy for Gwen's limited hearing and their ongoing support for her. They made conscious efforts to include her in conversations and they developed strategies that fostered her participation in the life of the care home, for example by ensuring that Gwen received information about communal events. One consequence of their support was the isolation that Gwen experienced in their absence:

Poor Gwen with her hearing, that is an awful handicap, my hearing isn't as good as it could be. I have a good hearing aid but I haven't got it here, I must get my son to bring it in and start using it as I notice sometimes my hearing is not as sharp as it could be. But Gwen is very dependant on Freda and Freda is very patient with Gwen, so Gwen always looks for her and she misses her when she's not there. In the summer when the weather's nice, Freda likes to sit outside and Gwen misses her. (Resident, study B)

These findings suggest that getting to know other people in the care home environment is a complex process. Residents may see each other in the communal spaces in the home but this does not necessarily result in meaningful interaction. These encounters do, however, provide opportunities for residents to exchange and receive information. In this narrative Gwen's ability to hear her fellow resident provided her with an unexpected opportunity for social interaction in what had been an isolating environment. Her hearing problems had resulted in her being disadvantaged in this environment, yet the support of fellow residents transformed this situation for her.

Maintaining interaction and developing relationships with fellow residents

As interaction between residents moves beyond the introductory phase, older people with sensory problems experience particular problems in their daily encounters with other people in the home. With so many people living and working in the same environment residents with sensory impairments experience difficultly in recognizing fellow residents following their initial introductions. When they fail to acknowledge other people that they have been introduced to, their actions can be misconstrued as they can be perceived as breaching normal social conventions.

The consequence of such breaches in social conduct is illustrated through the following narrative from study A that portrays the experiences of a woman who has limited and deteriorating vision. She made the decision to move to a care home when her chronic back problems, resulting from arthritis in her spine, led her to need continuous assistance in most aspects of her daily and personal activities. Since moving to the care home some 6 years ago she was diagnosed with a chronic visual problem. Initially this affected only her peripheral vision. Now she can only distinguish contrasting colours and only see forms as shadow.

Throughout many of the stories that she told about her life in the care home she highlighted the various ways that her visual problem led to difficulty in establishing and maintaining social interaction with other residents. In the following quotation she tells a story about other residents' reactions when she failed to acknowledge them:

Cause I am not a good mixer. I'll tell you what happens. I used to go down to the sitting room which is beautifully decorated with lovely armchairs and lovely furnishings and photographs. Really nice you

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couldn't get it more homely. They keep changing things around which makes things worse for me. Never mind. They will introduce me to somebody and I can sit and talk with them for a little while, not very long. I can't always understand what they are saying. And the next day, I wheel myself straight pass them and they think, she's a bit stuck up there. And they don't speak to me and I don't speak to them. We are like bits of kids, oh dear God. To think that I have come to this. I have been talking to a woman for ages and the next day I wheel myself past her because I cannot see her and I don't recognise her. (Resident, study A)

Her perceptions of other residents' views of her actions, as described in this passage, are grounded in a discussion that she overheard between two of her neighbours in the care home. Not only does she face difficultly in negotiating the ever changing physical environment of the care home, she also struggles to make sense of the social environment. In her daily life she faces continual embarrassment because she is aware that she continuously breaches normal social conventions when she fails to acknowledge others following initial introductions and discussions. These difficulties are both irritating and frustrating for her. In response she withdraws to her taped-books and avoids contact with other residents, consequently she spends a large proportion of her time in social isolation.

A similar situation arose in study B where a friendship between two women had become strained because of the hearing loss experienced by one of the women:

Well I don't go downstairs much now, there really isn't anyone I can talk to. I used to talk to Edith but her hearing has got so much worse that she can't hear anything I say now. I used to think she was ignoring me because she didn't speak to me. It's a pity but there you are. (Resident, study B)

The hearing loss of one woman contributed to the breakdown of a developed friendship that was not able to be replaced. This led to both women spending most of their time in their rooms, removed from the wider community of the home.

Discussion

These findings suggest that older people living in care homes can experience difficulties in interacting and making relationships with other residents due to their sensory impairment(s). Although sensory impairment is not the only factor influencing interaction between residents, the data in these studies suggest that this is a key factor in the interactions that do occur.

In other living environments the majority of people who enter are known to the occupant. In the case of strangers, these people are usually invited into the home by the occupants. Added to this the number of people entering and leaving an individual private residence is minimal. This is not the case in care homes. In these environments there is a constant movement of people and residents may or may not know everyone in the care home at any point in time. Consequently, the usual cues that individuals use to signify the presence of other people, and to assist them to recognize other people, are lacking in care homes. This is particularly problematic for people with limited vision and hearing as it provides challenges in day-to-day activities (Berry *et al.*, 2004).

Older people live in care homes with others whom they do not know and may not have anything in common with. It has been suggested that workers require greater sensitivity towards the impact of sensory impairment on social relationships between older people and others (Smith & Kampfe, 1997). However, staff in care homes are in a position to know people's backgrounds and subsequently facilitate introductions. Staff assisting the residents in study B to be seated in these positions, supported these relationships by providing the conditions for them to develop. However, it is unlikely that this was the only determinant for their interaction. These findings suggest that residents' support for one another to overcome sensory impairments was a key factor in the development of relationships with fellow residents. In the light of this evidence this would suggest that this would be a subject worthy of further investigation.

Being aware of and responsive to the needs of others is critical if interaction between residents is to include those with sensory impairment. Residents identifying themselves verbally to someone known to have visual impairment would enable that person to locate them without being dependant upon visual cues. Other simple, but important acts, such as facing someone with hearing difficulties to talk to them facilitates interaction. Such actions prevent misunderstandings that can be so damaging to the development of relationships with other residents. This would indicate that there is a need for further research to determine approaches that care staff can undertake to support residents with sensory impairment to sustain relationships with other residents beyond the initial introductions.

The narratives retold in this paper suggests that practice needs to develop in ways that are responsive to the needs and the circumstances of the older person to enable them to live the lives that they want to live in a care home.

Implications for the development of practice

The findings from the studies reported here are concerning given the evidence that sensory impairments and their impact

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on the lives of residents routinely go unacknowledged (Rees, 2004). Some residents may have marked sensory impairments yet they may have no specific 'label' or diagnosis, and this may make it difficult for staff to acknowledge a resident's problem. Added to this older people themselves may deny such problems (Mahoney, 1992; Cohen-Mansfield & Taylor, 2004). The cumulative evidence regarding this subject has led to acknowledgement of the need for improved detection and management of sensory impairment in the care home population (Flynn *et al.*, 2002; Cohen-Mansfield & Taylor, 2004).

Visual assessment, particularly assessment of functional vision should be routinely undertaken. Strategies range from simple questioning to identify sight loss to specific specialist tests to detect problems (Williams & Wallace, 1993; Disability Committee of the Association of Directors of Social Services, 2002). The Snellen chart is the most common form of visual acuity measurement and is available in 95% of GP practices (Featherstone *et al.*, 1992). By implementing these strategies treatable loss of vision experienced by older people may be detected, followed by appropriate referral for ophthalmological care (Tielsch *et al.*, 1995).

Hearing assessments can be undertaken easily through simple screening tools such as the Hearing Handicap Inventory for the Elderly (Demers, 2001) which identifies some of the difficulties the hearing loss may cause for residents. However, early clues can be identified by staff when residents misunderstand what is said or complain that people are speaking too softly (Rees, 2004) with appropriate referrals made to the GP for audiometric assessment.

A key aspect in the support of older people with vision and hearing impairments is ensuring that equipment is well fitted, positioned correctly and in good working order. However, nurses have been found not to have the awareness, knowledge or skills to achieve this (Tolson & McIntosh, 1992; Heron & Wharrad, 2000). Spectacles, if available, may not be cleaned and in the business of care home life may go missing. Limited dexterity of residents and lack of knowledge of workers has also been attributed to residents routinely not wearing hearing aids in care homes (Flynn *et al.*, 2002). Small details such as putting the hearing aid in a consistent place to avoid the risk of misplacement with all staff being aware of how it is stored, and how to turn it off to preserve batteries would be a positive step forward.

Care home staff can also fulfil a vital role in shaping environmental conditions that are conducive to optimizing resident's interaction with others, hence facilitating the development of relationships. The communal spaces in care homes do not allow people to manage their frailty as they may have done in more private environments (Barnes, 2002), and with respect to sensory impairment staff can take positive actions to create an enabling environment by managing the visual and 'listening environment' (Tolson & McIntosh, 1997) of the care home. Measures such as reducing background noise to give opportunities for quiet conversation, arranging seating to promote discussion in relaxed and sensory stimulating settings, and providing additional lighting are practical and achievable strategies. Without these types of interventions residents may avoid situations where they encounter difficulty in interacting with others and retreat to their own rooms, which potentially enhances their social isolation in the care home.

Finally there is a key role for care home staff to actively listen to what residents tell them about their daily lives as this will provide insights into how they can support residents to interact and develop relationships with each other. There is an important role for staff in being empathetic to the needs of residents and introducing them to others with similar backgrounds or interests and then identifying ways ongoing interaction can be facilitated. Equally, such information needs to be communicated through the care planning process. Interaction between residents is rarely included as part of formal documentation and this is an area that requires further exploration.

Conclusion

Neither of the studies reported here set out to consider the impact of sensory impairment on interaction and relationships between residents. However, the narratives and stories shared by older people in these care homes described how sensory impairment had a major impact on their social interaction. Furthermore, these findings suggest that staff awareness of interaction between residents and the impact that sensory impairment has on the development of relationships is essential if residents are to be supported. This would indicate that further empirical work is desirable in this area.

Author contributions

Study design: GC & CWB; data collection: GC & CWB; analysis and manuscript preparation: GC, CWB & DF.

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References

Age Concern (2004) *Older People in the United Kingdom.* Some Basic Facts 2004. Available at: http://www.ageconcern.org.uk/AgeConcern/CD60F3EDC34A44039297418428372 3E8.asp#Housing (accessed 18 January 2006).

Barnes S. & the Design in Caring Environments Study Group (2002) The design of caring environments and the quality of life of older people. *Ageing and Society* **22**, 775–789.

Berry P., Mascia J. & Steinman B. (2004) Vision and hearing loss in older adults: double trouble. *Care Management Journal* **5**, 35–39.

Bowie P. & Mountain G. (1993) Using direct observation to record the behaviour of long-stay patients with dementia. *International Journal of Geriatric Psychiatry* **8**, 857–864.

Bowling A., Banister S., Sutton S., Evans O. & Windsor J. (2002) A multidimensional model of quality of life in older age. *Aging and Mental Health* **6**, 355–371.

Cohen-Mansfield J. & Taylor J. (2004) Hearing aid use in nursing homes. Part I Prevalence rates of hearing impairment and hearing aid use. *Journal of American Medical Directors Association* **5**, 283–288.

Cook G. (2005) National Care Home Research and Development Forum. *Generations Review.* Summer edition.

Dalton D., Cruickshanks K., Klein B., Klein R., Wiley T. & Nondahl D. (2003) The impact of hearing loss on quality of life in older adults. *The Gerontologist* **43**, 661–668.

Dargent-Molina P., Favier F., Grandjean H., Baudoin C., Schott A., Haushem E., Meunier P., Breart G.; EPIDOS Group. (1996) Fall-related factors and risk of hip fracture: the EPIDOS prospective study. *Lancet* **348**, 145–149.

Demers K. (2001) Hearing screening. *Journal of Gerontological Nursing* **27**, 8–9.

Disability Committee of the Association of Directors of Social Services (2002) *Progress in Sight: National Standards of Social Care for Visually Impaired Adults.* CW Print Group, Loughton, Essex.

Eales J., Keating N. & Damsma A. (2001) Seniors' experience of client-centred residential care. *Ageing and Society* **21**, 279–296.

Farquhar M. (1995) Elderly people's definitions of quality of life. *Social Science & Medicine* **41**, 1439–1446.

Featherstone P.I., James C., Hall M.S. & Williams A. (1992) General practitioners' confidence in diagnosing and managing eye conditions: a survey in South Devon. *British Journal of General Practice* **42**, 21–24.

Fiveash B. (1998) The experience of nursing home life. *International Journal of Nursing Practice* **4**, 166–174.

Flick U. (1998) *An Introduction to Qualitative Research.* Sage Publications, London.

Flynn M., Kennedy E., Johns J. & Stanbridge R. (2002) Hearing and vision loss within residential care facilities – the need for improved service delivery. *Australasian Journal of Ageing* **21**, 141–144.

Gadamer H.-G. (1975) *Truth and Method.* Seabury, New York.

Grau L. & Wellin E. (1992) The organisational cultures of nursing homes: influences on responses to regulatory controls. *Qualitative Health Research* **2**, 42–60.

Guba E. & Lincoln Y. (1989) *Fourth Generation Evaluation.* Sage, Newbury Park, CA.

Heron R. & Wharrad H. (2000) Prevalence and nursing staff awareness of hearing impairment in older hospital patients. *Journal of Clinical Nursing* **9**, 834–841.

Hooyman N. (1983) Social support networks in services to elderly people. In *Social Support Networks: Informal Helping in the Human Services* (Whittaker J. & Garbarino J. eds). Aldine, New York, pp. 133–163.

Hubbard G., Tester S. & Downs M. (2004) Meaningful social interactions between older people in institutional care settings. *Ageing and Society* **23**, 99–114.

Kane R. (2003) Definition, measurement, and correlates of quality of life on nursing homes: toward a reasonable practice, research and policy agenda. *The Gerontologist* **43**(Special issue 11), 28–36.

Keller B., Morton J., Thomas V. & Potter J. (1999) The effect of visual and hearing impairments on functional status. *Journal of American Geriatrics Society* **47**, 1319–1325.

Keller B.K., Hejkal T. & Potter J.F. (2001) Barriers to vision care for nursing home residents. *Journal of American Medical Director* **2**, 15–21.

Kovach S. & Robinson J. (1996) The roommate relationship for the elderly nursing home resident. *Journal of Social and Personal Relationships* **13**, 627–634.

Lee G. & Ishii-Kuntz M. (1987) Social interaction, loneliness, and emotional well-being among the elderly. *Research on Aging* **9**, 459–482.

Lee P.P., Spitzer K. & Hays R.D. (1997) The impact of blurred vision on functioning and well being. *Ophthalmology* **104**, 390–396.

Llewellyn-Jones R.H. & Baikie K.A. (1997) Visual impairment and depression in residential care. *Medical Journal of Australia* **167**, 416.

MacDonald A., Craig T. & Warner L. (1985) The development of a short observation method for the study of the activity and contacts of old people in residential settings. *Psychological Medicine* **15**, 167–172.

Mahoney D.F. (1992) Hearing loss among nursing home residents: perceptions and realities. *Clinical Nursing Research* **1**, 317–332.

Marx M.S., Werner P., Cohen-Mansfield J. & Feldman R. (1992) The relationship between low vision and performance of activities of daily living in nursing home residents. *Journal of the American Geriatric Society* **40**, 1018–1020,

Mattiasson A. & Andersson L. (1997) Quality of nursing home care assessed by competent nursing home patients. *Journal of Advanced Nursing* **26**, 1117–1124.

McKee K., Harrison G. & Lee K. (1999) Activity, friendships and wellbeing in residential settings for older people. *Aging and Mental Health* **3**, 143–152.

© 2006 The Authors. Journal compilation © 2006 Blackwell Publishing Ltd

Mitchell P., Hayes P. & Wang J.J. (1997) Visual impairment in nursing home residents: the Blue Mountain Study. *Medical Journal of Australia* **166**, 416.

Mor V., Branco K., Fleishman J., Hawes C., Phillips C., Morris J. & Fries B. (1995) The structure of social engagement among nursing home residents. *Journal of Gerontology: Psychological Sciences* **50B**, 1–8.

Raynes N. (1998) Involving residents in quality specification. *Ageing and Society* **18**, 65–78.

Reed J. & Payton V. (1996) *Working to Create Continuity: Older People Managing the Move to the Care Home Setting*. Report 76. Centre for Health Services Research, University of Newcastle upon Tyne, Newcastle upon Tyne, UK.

Reed J., Cook G. & Stanley D. (1999) Promoting partnership with older people through quality assurance systems: issues arising in care homes. *Nursing Times Research* **4**, 353–363.

Rees T. (2004) Hearing loss: causes, symptoms and communication. *Nursing and Residential Care* **6**, 13–16.

Relatives Association (1997) *As Others See Us: A Study of Relationships in Homes for Older People*. Oakdale Printing Co. Ltd, London.

Resnick H.E., Fries B.E. & Verbrugge L.M. (1997) Window to their world: the effect of sensory impairment on social engagement and activity time in nursing homes residents. *Journal of Gerontology Social Sciences* **52B**, S135–S144.

Retinas J. & Garrity P. (1985) Nursing home friendships. *Gerontologist* **25**, 376–381.

RNID (2006) *Statistics*. Available at: http://www.rnid.org.uk/information-respurces/aboutdeafness/statistics (accessed 10 January 2006).

Rodwell M. (1998) *Social Work Constructivist Research*. Garland Publishing, New York.

Savishinsky J.S. (1991) *The Ends of Time: Life and Work in a Nursing Home*. Bergin and Garvey, New York.

Smith S. & Kampfe C. (1997) Interpersonal relationship implications of hearing loss in persons who are older. *Journal of Rehabilitation* **63**, 15–21.

Tate R., Smeeth L., Evans J., Fletcher A., Owen C. & Rudnicka A. (2006) *The Prevalence of Visual Impairment in the UK. A Review of the Literature*. Available at: http://www.rnib.org.uk/xpedio/groups/public/documents/publicwebsite/public_prevalencereport.doc (accessed 17 May 2006).

Tielsch J.M., Javitt J.C., Coleman A., Katz J. & Sommer A. (1995) The prevalence of blindness and visual impairment among nursing home residents in Baltimore. *The New England journal of Medicine* **332**, 1205–1209.

Tolson D. & McIntosh J. (1992) Hearing impairment in elderly hospital residents. *British Journal of Nursing* **1**, 705–710.

Tolson D. & McIntosh J. (1997) Listening in the care environment: chaos or clarity for the hearing-impaired elderly person. *International journal of Nursing Studies* **34**, 173–182.

Tolson D., Swan I. & Knussen C. (2002) Hearing disability: a source of distress for older people and carers. *British Journal of Nursing* **11**, 1021–1025.

Traupmann J., Eckels E. & Hatfield E. (1992) Intimacy in older women's lives. *The Gerontologist* **22**, 493–498.

Wallhagen M., Strawbridge W., Shema S., Kurata J. & Kaplan G. (2001) Comparative impact of hearing and vision impairment on subsequent functioning. *Journal of the American Geriatrics Society* **49**, 1086–1092.

Williams E.I. & Wallace P. (1993) *Health Checks for People Aged 75 and Over*. Royal College of General Practitioners, London.

Yueh B., Shapiro N., MacLean C. & Shekelle P. (2003) Screening and management of adult hearing loss in primary care. *Journal of the American Medical Association* **289**, 1976–1985.

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The risk to enduring relationships following the move to a care home

Glenda Cook BSc (Hons) (Psy), MA (Medical Ethics), RGN, RNT
Principal Lecturer, Northumbria University, Newcastle upon Tyne, UK

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Correspondence:
Glenda Cook
Room H017
Coach Lane Campus East
Northumbria University
Newcastle upon Tyne NE77XA
UK
Telephone: +44-191-2156117
E-mail: glenda.cook@unn.ac.uk

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The risk to enduring relationships following the move to a care home

Aim. To explore findings from a study which investigated the meanings that older people attributed to their experiences of living in a care home and consequently the risks that they identify in this.

Background. There is evidence from this and other studies that being able to engage in long-time friendships is important to older people. The move to a care home has the potential to disrupt these relationships and there is a risk of breakdown of the friendships that have been valued throughout life.

Method. A hermeneutic inquiry that explored the meaning that eight older people ascribed to their life in the care home. This paper focuses on the narratives that concerned relationships with long-time friends and the risks to these relationships.

Results. The paper highlights the importance of engaging in meaningful relationships with other people. The participant's stories illuminated the importance of maintaining friendships following the move to a care home and how these had had a positive impact on their lives in that setting. With advancing age and increasing frailty the participants were acutely aware that their friendships were vulnerable to breakdown and they implemented a range of strategies to sustain their relationships with these people.

Conclusion. The findings point to the importance of acknowledging the value of long-time friendships to older people and the need to support them in their efforts to sustain these relationships and reduce risks to them.

Key words: care homes, friendship, narratives, older people, relationship, residents

Introduction

With the move to a care home, older people face significant changes to their social networks. Whilst there is the possibility of developing new relationships as they meet and get to know fellow residents and the staff working in the home (Reed & Payton, 1996; Hubbard *et al.*, 2004), they may experience difficulty in sustaining the same quality of relationship with family and friends. Changes in social relationships, particularly where there is reduction in interaction with those that have been a significant part of a social network, is important because social engagement is known to be an important influence on self-perceived quality of life, life satisfaction and well-being in later life (Ishii-Kuntz, 1990; Farquhar, 1995: Bowling *et al.*, 2002).

The impact of a move on an older person's relationships with family and friends can be experienced immediately following the move to a care home. Their interaction with these people is reduced to visits and other factors such as the geographic location of the home may pose problems to people keeping in touch with each other. When they do meet, familiar patterns of interaction may no longer exist and this may put a strain on the relationship.

This suggests that the period of moving-in involves a process of separation for the new resident. One response to this is that relatives implement strategies to maintain continuity in their relationship with the older person (Sandberg *et al.*, 2001). The value of maintaining interaction has been widely reported with accounts of family involvement facilitating individualized care, providing links to the older

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person's history and their preferences, and enhancing the quality of life of the resident (Ekman & Norberg, 1988; Rowles & High, 1996; Friedmann *et al.*, 1999). Although studies have indicated that the support of friends in later life can be more important to self-perceived well-being than the support of families (Larson *et al.*, 1986; O'Connor, 1995), the same attention has not been given to the impact of relocation on friendships nor to understanding the approaches that they adopt to maintain their relationship.

Relationships with family and friends are different. Rather than developing from familial ties, friendships emerge from intimacy, mutual understanding and reciprocity with another person (Jerrome, 1993). In a review of the literature, Slater (1995) concluded that the value of friends in later life rested in opportunities to give and receive aid, affect and affirmation to one another.

Throughout life, people give emotional investment to establishing their friendships and by later life they have had the opportunity to sift through acquaintances and friends, retaining those that are most valuable. Finchum and Weber (2000) argue that decisions to sustain relationships in later life are made in the context of lifelong social preferences and experiences, including geographical location, class, race, gender, backgrounds and interpersonal styles.

In later life, peer group similarity becomes increasingly important as part of life continuity, particularly as many older people experience shrinkage in their social networks as their peers die, become less active or relocate. Whilst there is evidence that friendships in later life tend to be very stable and enduring (Field & Minkler, 1988), older people do continue to make new friends (Jerrome & Wenger, 1999). Although important, new friendships cannot replace the deep familiarity of long-term friendships where individuals have experienced the trustful sharing of experiences, thoughts and feelings.

This paper contributes to an understanding of the threats that the move to a care home imposes on enduring relationships by re-examining data from a study that explicitly sought to examine daily life from the perspective of care home residents. Descriptions of the ways that older people actively work to sustain their friendships are reported here. Whilst the stories that they told highlighted the importance of their interactions with their family, fellow residents and staff, the focus of this paper is on friendships.

Methods

The study was a hermeneutic inquiry (Gadamer, 1975, 1976) that sought to investigate the meanings that older people attributed to their experiences of living in a care home. The research design explicitly aimed to facilitate frail older people to tell stories of their life in a care home and to move beyond public stories to tell of their private inner world – their joys, struggles and reactions to residential living. For this reason narration was adopted as the data collection method in the inquiry. This study involved eight residents who were living in four different care homes. The participants were invited to take part in a sequence of a maximum of eight interviews that were carried out over a period of 4–6 months. This resulted in a total of 53 interviews with residents.

The study sought to develop a shared understanding between the older people and researcher. This was achieved using an iterative process between data collection and analysis followed by the researcher verifying understanding with the participants, thus contributing to a shared perspective on the interpretation of the data.

Findings

The value of friendship

For many of the participants, visits, telephone calls or letters from close friends were a feature of their life in the care home that they valued. Regular visits from the same friend were particularly welcomed. Their exchanges enabled the resident to keep attuned to events that were happening in the wider community. Those who were able to meet with their visitors in their own rooms enjoyed companionship with a trusted friend. Often this involved sharing some food, talking and enjoying some form of entertainment together. One woman described these meetings as her 'night-in' that were somewhat reminiscent of the 'get togethers' that she had enjoyed with neighbours and friends in her own home. The fun and mutual pleasure that friends share is captured in the following story that she told:

> on a Thursday night when my friend comes we watch the television together. She likes her Emmerdale and Who wants to be a millionaire?. I like that one also. We chat and she says 'Oh you have won such and such,' and I go 'Alright and I have £500 – shall we half it?' ' Get to the £1,000'. 'That's £500 each we've got'. Silly old biddies. But it is a good program. She reads the questions out. If I was on my own and put it on I couldn't see the questions. That's the only time that I have it (the television) on. Pointless because I can't keep up with the stories.

Being able to experience a deep intimacy with another person was characteristic of this type of interaction, which was lacking in their intra-institutional relationships. Long-term friends shared confidences with each other and the resident was able to share concerns (for example, about financial

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issues and deteriorating health) with these people without being concerned about burdening younger members of their family. They also tended to ask these people to run errands for them in the knowledge that their friend would return in the near future. Another feature of these relationships was the way that friends provided assistance to enable residents to do things that they found personally meaningful. In the following account a male resident described the way that his friends supported him to enjoy some time out of the care home:

I would be quite, more than content if I had another night out. But I suppose there again I am thankful that I can get a night out. Because this lad who takes me out comes from G. and comes every Tuesday night. So I am thankful that I have somebody that can do that.

Researcher: Yes. Where do you go to?

B. Rugby Club. Oh I have had some good friends. There was two of them. One lives at K. and one lives at Sth G. They are golfing friends of mine and they come twice a week – Tuesdays and Fridays from the day I took bad. So that is six years every Tuesday and every Friday. I think that is marvellous that you can have friends like that. They are what you call friends. And two other friends come just when they can. Well you never know when they are coming.

Although he enjoyed the occasional visits from other people that he knew, in this account he pointed out the difference that it made to his life to be able to count on the regular support of trusted friends.

Although these older people defined their friendships with other people in different ways, they did make a distinction between their long-term relationships and other forms of interaction that they experienced. There was a level of emotional intensity in these relationships that enhanced the quality of their life in the care home.

Strategies residents adopt to maintain long-term friendships

Through their stories these older people made reference to the advanced age of their long-time friends and to their changing circumstances. One woman, at the age of 95 years had outlived all of her peers. Others had experienced the death of at least one or more of their close friends. Of their surviving friends, illness and disability had the potential to lead to a breakdown in their relationship if they were unable to contact one another. The residents felt that their own frailty and illness limited the type of assistance that they could offer to maintain their relationship with their friends.

Although they were limited in what they could do, they did work actively to sustain friendships. In some situations they negotiated changes in the ways that they interacted with friends. For example, the women who visited her friend on a Thursday night (see above) initially visited the home three times per week. As the years passed by and the Parkinson's disease she experienced began to affect her mobility it was the resident who broached the subject of changing visiting arrangements. At first her friend resisted the notion of meeting less often, but did eventually agree to their 'night-in':

I said, 'Now look, you are doing far too much'. (She was trying to help her grand-daughter with the new baby and continue visiting.) It wasn't doing her any good so we cut it down to one night per week. So she comes on a Thursday night. But she is always there 6.30pm on the dot.

In other situations the residents developed alternative ways to keep in touch with friends:

and another friend she comes nearly every day. I have not got many left now and two are away at the moment and my friend in D. she had a fall. She is about 20 years younger than me. She was in hospital for a while so she couldn't get over. I rang my friend and could not get in touch, so I thought that I had the wrong number as I couldn't get hold of her. You see I don't use the phone very much you know. I am not at all good on the phone now (as a consequence of her speech difficulties following a stroke). But I manage, that is the main thing.

This woman occasionally phoned her friends from the privacy of her room, however, the expressive aphasia that she suffered from caused difficulty in taking part in long conversations. Through negotiation with the activities co-ordinator she enlisted the support of care staff who took dictation from her. In this way she sent and received letters from friends. This suggests that some of the strategies that older people adopt do need the recognition and support of care staff if they are to be successful in their endeavours to sustain their friendships.

The importance of friendship

The stories retold here, indicate that older people value their intimate ties with long-term friends and want to sustain these beyond the move to a care home. When residents are with their friends they experience deep feelings of intimacy and peace, and importantly they continue to share thoughts and feelings with people that know and understand them.

The move to a care home poses a threat to the friendships that older people cherish. With advancing age and increasing frailty, residents are acutely aware that their contribution to their friendships with others is lessened. Friendships in their earlier life were characterized by mutual reciprocity and a

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sharing that is no longer possible. The findings highlighted the ways that these older people found to reciprocate the actions and the giving of their friends by recognizing and responding to their emotional needs. This was reminiscent of Jerrome's (1990) conclusion that mutual satisfaction of emotional need in old age friendships is more important than being able to reciprocate aid or contribute equitably to the relationship.

In recognition of the vulnerability of their long-time friendships, the residents implemented a range of strategies to sustain their relationships. They needed some support to do this. These findings suggest that there is a place for care home staff in recognizing residents' friendships and in supporting their efforts to sustain these. Practical measures such as making friends welcome in this new environment and supporting residents to write letters or to use communication aids such as telephones, mobile phones and email where computers are accessible would help residents to keep in touch with their friends. Residents value the opportunity to meet with their friends in private, so creating the means for residents to entertain friends in their rooms is conducive to supporting friendships. The older person's friendship structures are rarely addressed in care plans – the difficulty being that friendships may not be recognized nor supported. Addressing this subject would be a step in the right direction to enhance the quality of life for care home residents.

Friendship and risk

This paper has focused on a particular aspect of risk that older people face when they move to a care home. The discussion has highlighted the value that older people attribute to their long-term friendships and the efforts that frail older people make to sustain these beyond the move. Breakdown of enduring friendships, therefore, is a significant and negative life event to residents.

Risk to social engagement, as it has been examined here, is not a prominent subject within the academic and practice literature. This is, however, a feature of care home life that is of equal or perhaps of more importance to older people than the many other risks that they encounter to their physical or emotional well-being.

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References

Bowling A., Banister S., Sutton S., Evans O. & Windsor J. (2002) A multidimensional model of quality of life in older age. *Aging and Mental Health* 6, 355–371.

Ekman S.L. & Norberg A. (1988) The autonomy of demented patients: interviews with caregivers. *Journal of Medical Ethics* 14, 184–187.

Farquhar M. (1995) Eldery people's definitions of quality of life. *Social Science and Medicine* 41, 1439–1446.

Field D. & Minkler M. (1988) Continuity and change in social support between young-old and old-old or very-old age. *Journal of Applied Gerontology* 43, 100–106.

Finchum T. & Weber J.A. (2000) Applying continuity theory to older adult friendships. *Journal of Aging and Identity* 5, 159–168.

Friedmann N.L., Montgomery R.J., Rice C. & Farrell L. (1999) Family involvement in the nursing home. *Western Journal of Nursing Research* 21, 549–567.

Gadamer H.-G. (1975) *Truth and Method*. Seabury, New York.

Gadamer H.-G. (1976) In *Philosophical Hermeneutics* (linge D. ed.). University of California Press, London, pp. 181–209.

Hubbard G., Tester S. & Downs M. (2004) Meaningful social interactions between older people in institutional care settings. *Ageing and Society* 23, 99–114.

Ishii-Kuntz M. (1990) Social interaction an psychological well-being: comparison across stages of adulthood. *International Journal of Aging and Human Development* 30, 15–36.

Jerrome D. (1990) Frailty and friendship. *Journal of Cross-cultural Gerontology* 5, 51–64.

Jerrome D. (1993) Intimate relationships. In *Ageing in Society: An Introduction to Social Gerontology*, 2nd edn (Bond J., Coleman P. & Peace S. eds). Sage, London, pp. 181–209.

Jerrome D. & Wenger G.C. (1999) Stability and change in late-life friendships. *Ageing and Society* 19, 661–676.

Larson R., Mannell R. & Zuzanek J. (1986) Daily well-being of older adults with family and friends. *Psychology and Aging* 1, 117–126.

O'Connor B.P. (1995) Family and friend relationships among older and younger adults: interaction, motivation, mood and quality. *International Journal of Aging and Human Development* 40, 9–29.

Reed J. & Payton V. (1996) *Working to Create Continuity: Older People Managing the Move to the Care Home Setting*. Report 76. Centre for Health Services Research, University of Newcastle upon Tyne.

Rowles G.D. & High D.M. (1996) Individualizing care: family roles in nursing home decision making. *Journal of Gerontological Nursing* 22, 20–25.

Sandberg J., Lundh U. & Nolan M. (2001) Placing a spouse in a care home: the importance of keeping. *Journal of Clinical Nursing* 10, 406–416.

Slater R. (1995) *The Psychology of Growing Old: Looking Forward*. Open University Press, Buckingham, Philadelphia.

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