

THE UNIVERSITY OF HULL

Moving Home: Exploring older peoples' experiences of hospital discharge.

being a Thesis submitted for the Degree of Doctor of Philosophy
in the University of Hull

by

Clare Frances Whitfield BA (Hons) RGN

April 2009

CONTENTS

Tables and Figures	...	iv
Acknowledgements	...	v
CHAPTER ONE Older People and their Access to Support	...	1-21
1.1 Older People and Support	...	1-4
1.2 The Production of Care Experiences	...	4-11
1.3 Towards an 'Experiences Model'	...	12-18
1.4 Declaring an Interest	...	18-21
CHAPTER TWO Mind the Gap: A Review of the Context	...	22-61
2.1 Policy Production, Implementation and Practice	...	24-42
2.2 Economic Interests and Issues of Funding	...	42-53
2.3 Cultural Issues: ageism, sexism and professional conflicts	...	53-61
2.4 Why Listen: 'Hearing' older people's experiences	...	61
CHAPTER THREE Exploring Older People's Experiences: The Methodology	62-135
3.1 Design: Choice of Methodology and Methods	...	62-82
3.2 Data Collection: Sampling, Access and Ethics	...	82-98
3.3 Data Analysis: Uncovering Categories	...	98-108
3.4 Issues of Rigour: Fit, Work, Grab and Modifiability	...	108-112
3.5 Who's Who: An Outline of Individual Situations	...	112-135
3.6 Summary	...	135
CHAPTER FOUR Going Home: The first level of analysis	...	136-249
4.1 Making Decisions	...	139-170
4.2 Feelings of Independence	...	170-201
4.3 Matters of Concern	...	201-221
4.4 Managing Change	...	221-247
4.5 Matters Arising: Discussion	...	247-249

CHAPTER FIVE Managing Change: The second level of analysis	...	250-336
5.1 Links within Themes: developing dimensions	...	250-312
5.2 Links between Themes: developing a model	...	312-314
5.3 The Core Category: Managing Change	...	314-334
5.4 Summary	...	335-336
CHAPTER SIX Conclusion and Recommendations	...	337-373
6.1 Discussion of Findings	...	337-359
6.2 Review of Quality	...	360-369
6.3 Policy Recommendations	...	369-371
6.4 Further research	...	371-373
References	...	374-424
Appendices	...	425-431

Tables and Figures

Table 3.1	Showing the initial grouping of experience codes that emerge from discussions with older people during a series of three unstructured interviews	...	103
Table 4.1	Showing experiences codes and emerging subcategories at the stage where dimensions are identified	...	137-138
Table 4.2	Showing the results of open coding as experience codes are organized as categories and their emerging subcategories	...	248-249
Table 5.1	Showing the categories and their dimensions	...	251
Table 5.3	Showing categories, dimensions and properties	...	312
Table 5.5	Showing a summary of the categories and dimensions of the core category Managing Change	...	315
Table 5.6	Showing the dimensions and properties of the core category Managing Change	...	325
Table 5.7	Showing the facilitators and barriers to Managing Change	...	326
Figure 1.1	To show a graphic illustration of policy intention	...	12
Figure 5.2	Representing a range of approaches to managing changes	...	311
Figure 5.4	Showing an initial model of the relationship between the categories	...	313

Acknowledgements

I would like to thank the University of Hull for their sponsorship and my supervisors, Dr Julie Seymour and Professor Roger Watson, who have supported me through the second half of my PhD with unswerving good humour. I would also like to acknowledge the help and good guidance I received from Jill Manthorpe and Dr Jenny Hockey, who set me on the right road. I would not have completed this piece of work if I had not had the support and understanding of my children, Jack and Joe Newman. A particular thank you must go to my friends, Sharon Eastwood, Ian Carroll, Susan Rogers, Martin Newman, Jane Aisbitt and Nicola Blake-Barnard, who listened. Finally, thank you to Ian Thorpe for his dedicated proof reading.

This thesis is dedicated with love to
Jean Ann Whitfield and Michael Whitfield.

CHAPTER ONE

OLDER PEOPLE AND THEIR ACCESS TO SUPPORT

1.1 Older People and Support

The overall aim of this research project is to investigate the impact of government policy, professional practice and social attitudes on the experiences of the older person leaving acute hospital care and returning to their own home. The project aims are summarised as below:

- To develop an understanding of individuals' experiences within discharge preparation and planned support while they are preparing for home, getting home and being home.
- To explore older people's experiences of co-production in the definition of needs and planning support to meet these needs.
- To investigate the 'appropriateness' of the discharge package (plan or pathway) as seen by the individual once home.
- To develop a model that allows a structured comparison between individual experiences and policy aims.

Exploring older people's experiences of the health and social care system as they leave hospital and return home is important and pertinent for a number of reasons. Firstly, we live in an ageing society. The 2001 Census showed that there had been a fivefold increase in those over 85 years since 1951, now 1.1 million people. In

2005 there were more than 11 million people of state pension age and over living in the United Kingdom (*Population Trends 2006* cited in Age Concern 2007). People are living longer; there is an increased number of the 'oldest old', for example by mid-2007, in the United Kingdom, it is estimated that 11,000 people will be aged 100 and over (Tomassini 2005). This represents an increased life expectancy for both men and women: a 60 year old for example could expect to live for another 20.5 years if a man and 23.6 years if a woman (ONS 2006). This raises a number of pressing issues: the need for an equitable mechanism to distribute limited resources, a debate to identify how and how much, we as a society pay for this growing need for support, and how is 'care' to be structured so that it is meaningful. On a personal level, ageing has implications for all of us, as getting old and being old are part of the natural process of living and is something we will all experience, if we are lucky.

Secondly, older people are traditionally seen as 'vulnerable', with reduced access to autonomy over their own lives (Hockey and James 2003) and a consequent reduction in independence leading to a low 'quality of life' (Katbamna *et al.* 2002). To address these issues, to improve the quality of life and care for older people and to maintain independence for as long as possible, New Labour seeks to provide older people with a 'voice' at all levels (DH 2001a, Glasby 2005). That is, at a structural level, in relation to political participation and the reduction of ageism within society as a whole; at an organisational level, in relation to consultation and the participation of older people in research commissioning and the research process, policy development and evaluation, local implementation and the provision of services; and at an individual level, as older people are placed

at the heart of assessment and decision-making about their own support needs through the provision of person-centred care (*National Service Framework for Older People* DH 2001a, *Guidance on the Single Assessment Process* DH 2002a). One aim of this thesis is to explore the extent and effectiveness of individual participation in the discharge process.

Thirdly, following from this, discharge represents a complex experience where effective and accurate decision-making is vital to how well an individual manages once home (Waters *et al.* 2001, Walker *et al.* 2007). Planning that aims to promote independence must take older peoples' views as a starting point (Lloyd 2006), indeed, more appropriately, must build on older peoples' existing strategies for meeting their own needs and maintaining a subjectively defined, good 'quality of life' (Tanner 2007).

However, discharge from hospital also represents a time when older people are vulnerable to the imposition of external agendas, such as agency concerns and the requirements or availability of informal, as well as formal, sources of support (Lloyd 2006). Therefore, a further aim of this project is to explore older peoples' experiences of the discharge process in order to identify whether older peoples' wishes and strategies structure discharge planning.

Fourthly, an exploration of the discharge process is important as the return home from hospital represents a point at which older people move from medical and acute health care to social and daily 'other' support. This represents an interesting focal point, that allows a glimpse at firstly, how the individual and the health and

social care system interrelate and secondly, the individual experience of moving from one to the other.

Finally, policy aims do not always translate into actual outcomes. Unintended outcomes can impact on an individual's ability to cope, detract from their quality of life or curtail the autonomy they have over how they live their daily lives. A main concern is the desire to uncover these gaps between intention and outcome and to establish how well and in which areas policy aims are met in the experience of those with support needs.

1.2 The Production of Care Experiences

Central to this debate is the disjuncture between what is planned for in policy and in the codes and values of professional practice and what is experienced by older people in the moment of care. Underlying these gaps between policy intentions and the lived experience are the dynamics of power, which work on two levels; at the macro level, through 'societal forces' and at the micro level, through 'relations of care'.

1.2.1 Societal Forces

Older peoples' care experiences are patterned by a number of external forces at all levels; structural, organisational and individual (Glasby 2005). These forces shape the experiences of older people, as they impact on the construction and aims of policy, the quality and range of services available, and the types and equability of mechanisms available to assess needs and access support. Macro-power dynamics are apparent in the shaping of services for older people, in the interplay between

different structural pressures that partially construct the social context in which we live.

Our population is ageing within a particular political, economic and cultural environment. As there are an increasing number of older people requiring increasingly more expensive treatment and support, for longer, the issue of the distribution of limited resources is all the more pertinent; essentially the debate centres around two questions: who will receive what types of support and who will pay. Alongside this is the rise in popularity of concepts such as equality of opportunity and social justice which are central to democratic thought and embedded in consumerist discourse. Questions surround how we manage resources. How will we provide a cost-effective support service in a way that will allow an acceptable quality of life through autonomous decision-making? Wider cultural issues also impact on the care experiences of older people, in terms of the limiting effect of living within an ageist society. Discriminatory attitudes potentially shape and distort the relationships within which older people live as a social group and as individuals.

The types, quality and accessibility of support available to people returning home from hospital, and how resources are targeted, are governed by social and health policy. This is produced by government, and is therefore influenced by dominant political ideology, that contains within it a particular approach to economic and resource management, to the individual and their relationship with the 'State' and therefore to the mechanisms that manage the match between people with needs and the support to which they have access. Hence the resources required to

support older people in their maintenance of independence and dignity are also managed at these three main levels: structural, organisational or individual (Glasby 2005).

Structural political concerns include an increase in the popularity of concepts such as consumerism and the rights of citizens; however also included is the hegemonic work of the political ideology of those who have power in the country. At an organisational level, the central concern is the equality of access to care for those in need. Care and commissioning judgements focus on individual need and are not made on the basis of age (DH 2001a). At the individual level important issues include: maintaining the balance between 'rights and responsibilities' by ensuring 'choice' is available to those receiving support. Policy intentions are, in reality, not met in some areas for some people and for a variety of reasons. Firstly, policy development, although research based, does not represent a full implementation of research findings (for example *The Sutherland Report*, The Royal Commission on Long Term Care 1999). These are instead interpreted through political and economic ideology, so reducing the validity of the research base. Recognition of contingent and contextual factors that affect research findings is also necessary.

Research findings are not 'neutral' or bias in themselves, but reflect in part the views, interests and assumptions of the researcher and the context within which they work (Darlington and Scott 2002, Silverman 2001). Furthermore, the rise in 'consumerist' values within the planning and provision of support services for older people leaving hospital and returning home is related to the prominence of consumerism within society as a whole (Waters *et al.* 2001, Ferguson 2007).

Structural economic concerns centre on achieving cost-effective support provision: the question of who pays for what. A further point here, and in many ways more important, is the economic relations of the production of 'care'. In other words, those who make money out of providing support and treatment for older people must be viewed in a critical light if the reality of older peoples' support experiences is to be fully understood. At an organisational level decisions surrounding which professional specialisms get what funding, require an equally critical view to understand the problems that leave care of older people as a 'Cinderella service' as well as those policies that are antagonistic to the aim of providing an holistic organisational approach (*Delayed Discharges* DH 2003b, Glasby 2003a, 2003b, Glasby *et al.* 2004, Glasby 2005). On an individual level, older people exist in a market economy of care, therefore there are those who have the economic capital to access certain support services and those who must rely on means tested support. This means test is apparent in two ways: firstly, through the eligibility criteria that govern access to formal and in some cases the feasibility of informal, support arrangements and secondly, by the definition of a need as being health or social care, as different funding issues impact on the provision of services.

Secondly, the inclusion within NHS provision of ever more sophisticated and expensive treatments, as well as the increasing medicalisation of everyday life, especially of 'older age' (Katz 1996), brings notions of resource distribution to the fore. How resources are 'targeted' reflect political ideologies and interests as well as wider economic and hegemonic (Gramsci 1971) interests of biomedical

companies (such as the pharmaceutical industry) and medical industries, including doctors, medical and care ‘experts’ (Illich 1976, Katz 1996).

Finally, structural cultural issues shape the types of care older people experience; that is, the impact of ageism through the lay acceptance of old age as associated with ‘vulnerable’ ‘decrepit’ and ‘dependent’. Professional conflicts and implicit ageism in the implementation of services at an organisational level shape individual experiences of care (Dalley 2000, Atwal 2002). Wider issues of ageism, sexism and cultural clashes between different professional views also pattern what support is available to older people and what access to support options they experience in reality. Cultural issues are pertinent within the moment of care-giving as well as in the opportunities available to older people to access autonomous decision-making in planning, implementing and evaluating care. They also have an impact on access to appropriate and empathetic support. These issues are explored in more depth in Chapter Two.

1.2.2 Relations of Care

Micro-power relations define, in part, older peoples’ experiences of receiving care. Support is given and received within the social relations of care, that is, the experience of accessing support services and receiving care in the moment is achieved through social relationships between older people and those that provide support and help them (Powell and Biggs 2000, Powell 2001). Within the moment of care, micro-power dynamics are part of the social relations of care and shape the level of appropriate support an individual can access. The concepts of social and cultural capital (Bourdieu 1986) are relevant here as different levels of such capital can impact on the access to care an individual has in the assessment of

needs, in the planning of help and, pertinent here, in the accessing of appropriate formal and informal support in the moment of giving and receiving care.

Capital can be seen as a social relation within a system of exchange (Jary and Jary 2005). Social capital refers to the resources an individual has in terms of group membership, and both actual and potential networks of influence and support. It can be defined as: “features of social organisation such as networks, norms and social trust that facilitate coordination and cooperation for mutual benefit” (Putnam 1995: 67). Social capital exists only within relationships (Fukuyama 1999) and is a feature of the social context (Bolin *et al.* 2003). Cultural capital represents the forms of knowledge, education and skills an individual has access to that increase their status (Bourdieu 1986).

For older people, healthy social relationships are central to positive experiences of receiving effective informal support (Wenger and Tucker 2002). They also influence formal views of an individual’s ability to help themselves in getting the support they need. Having a ‘supportive family’ can identify the individual as a ‘successful older person’. High social capital can increase access to informal advocacy, again increasing the potential to access appropriate formal support. However, older people are not always in a position to take part in supportive social networks (Hockey and James 1993, 2003, Wenger 1997, Wenger and Tucker 2002) especially when reduced mobility becomes a barrier to socialising opportunities; this in turn, reduces their potential to access appropriate informal support.

Access to cultural capital may increase the availability of information as well as the provision of successful advice and advocacy. It allows older people to request information and advice from formal workers in the right language as well as enabling them to make sense of the information and advice they receive as a result. Furthermore, it can increase respect amongst staff and confirm an older individual as ‘capable’ and competent in the decision-making surrounding the planning and implementation of care pathways. This is essential as the relationships older people have with those who support them impacts on the levels of participation in the process and autonomy in decision-making to which they have access.

Cultural capital is relative to the ‘field’ of social relations within which a person is engaged (Bourdieu 1986). For older people, therefore, the cultural elements they possess may have differing status depending on the type of care relations within which they are situated. Informal care provision in the moment of care may represent a very different field to that which they inhabit when accessing formal support. Older people who possess cultural capital that is given status by those who help them, may be advantaged in accessing respectful relationships that are central to the experience of person-centred, dignified care (DH 2000a, 2001a, 2002a, *Opportunity Age* DWP 2005, *A New Ambition for Old Age* DH 2006a).

These micro-power relations reflect wider macro level issues (Mills 1959, Bourdieu 1973, 1986, Giddens 1979, 1984, Moats 2006). Older people are disadvantaged and their cultural capital threatened through the inclusion of ‘the individual’ as conceptualised in consumerist ideology (Hockey and James 2003)

and this in turn can act as a barrier to accessing appropriate care. If they have low economic capital then they must rely on their social capital, in terms of family, friends and their wider support and social network (Wenger 1997). Support for older people as outlined in policy, aims to ameliorate the unequal effects of differing levels of individual capital, through person-centred care and a service that is 'seamless', user-led and needs-led, with financial help focussed on those with the most need. This is implemented through the provision of person-centred care and through the appropriate application of the eligibility criteria (DH 2001a, DH 2001e, DH 2002c, McCormack 2004).

Micro-power dynamics and the different levels of capital held by different actors shape the experiences older people have in terms of planning support and receiving care in the day-to-day. This can result in unintended consequences for individual older people, for example, caring for older people is largely seen as non- or low skilled 'dirty work' (Finch and Mason 1993, Anderson 2000).

Underlying policy contains an assumption that these skills are available in day-to-day, intimate and personal support, but those who provide formal semi-professional support (personal assistants and domiciliary workers) do not necessarily have advocacy and counselling skills, nor anti-discriminatory ethical training. Levels of training, skills and financial resources, the type of culture that exists within formal and informal support relationships, and the reality of power dynamics within these encounters reflect wider political, economic and cultural forces and compromise a faithful implementation of research based solutions (Joseph Rowntree Foundation 2004). This issue is discussed further in Chapter 5.

1.3 Towards an ‘Experiences Model’

Policy states that support provision for older people should not be ageist nor led by professional or resource agendas, but instead should be person-centred and needs-led, where, in an ideal setting, older people are empowered to take a proactive role in exercising their autonomy and defining their own needs (*The NHS Plan* DH 2000a, *National Service Framework for Older People* DH 2001a, *Better Health in Old Age* DH 2004b, *A New Ambition for Old Age* DH 2006a). I have provided an initial summary of the combined aims of policy as represented below (see Figure 1.1).

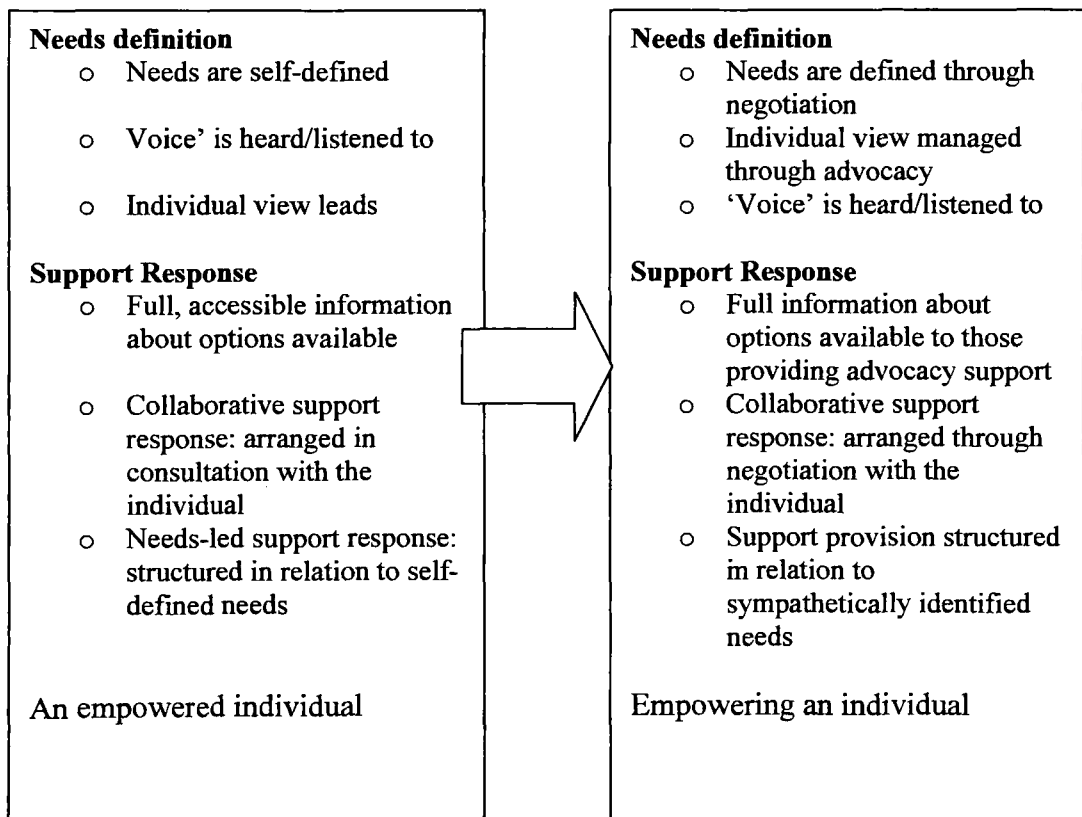


Figure 1.1 Showing a graphic illustration of policy intention

The intentions of policy that governs the access older people have to differing types of support has been criticised in its construction and in its relation to the lived experience.

The aims of policy are to promote autonomous decision-making amongst older people; to consider their wishes and understandings as the starting point for discharge planning; to provide 'joined up' services, that are effective and sustainable and to give older people access to a good quality of life as they see it and the provision of support for those who have no other form of access. These aims reflect concepts central to consumerist models in the provision of health and social care support for older people going home. The focus on older people as consumers and 'service users' raises a number of relevant issues, which may compromise achieving the policy aims that are described above, in a number of ways.

First, producing policy which declares older people as autonomous and proactive care consumers living within an empowering environment expresses an ideological position but does not mean that this is the case in reality (Tracy and Ronayne 2000: 24); for example, resource constraints can compromise policy intentions (JRF 2004).

Secondly, the experience of 'being old' is heterogeneous; that is it is different for different people. Not all older people will be able to take a 'pro-active role' due to a lack of experience in voicing an opinion, the cultural understanding that the 'doctor knows best' or as a result of other structural barriers (Roberts 2002).

Central to consumerist notions of the individual is the ideal of youth; this makes 'being old' a disadvantage, which is further compounded when older people are not able to 'compete' with younger people (Hockey and James 2003, Ferguson 2007). In addition, with the increase in numbers of older people and the extension of life expectancy, two 'classes' of older people become apparent: the old-old (75 years and over) and the oldest old (over 95 years) (Grundy 1997, Tomassini 2005).

Arising from this is the potential for ageism, through the 'othering' of older people, especially the oldest older people, as being different to the youthful norm and ideal.

A third issue follows from this. If there is incongruence between how the individual is conceptualised in policy and the lived experience of being an older person with support needs then policy aims may not have the intended outcomes. Furthermore, inconsistencies may arise as a result of ineffective implementation through local policy and practice. Research indicates (Aronson 2002) that a gap exists between the aims and outcomes of policy, therefore participation, choice, holism, independence and equality of opportunity, concepts which are central to a consumerist approach, are not necessarily accessible or part of older peoples' experiences of leaving hospital to return to support at home.

Fourthly, the individual's understandings and wishes are seen as crucial to the co-production of an appropriate and sustainable support plan; however, there is no modelled way of considering the experiences older people have of different management approaches to planning, implementing and evaluating the discharge process. By developing a model that allows a comparison between older peoples'

individual experiences, as well as the stages of the discharge process, the instances where policy aims are not met can be identified and addressed.

The user view is essential in providing a fuller understanding into the way the discharge home from hospital 'feels' for those experiencing it. For professionals managing processes such as discharge, care planning and identifying types of care most appropriate to meet certain issues has a logical pathway where the strategies adopted reflect training, research and hospital protocol; older people experience the move from hospital to home as a 'whole', as a 'lived' experience. Where the professional meeting of needs is categorised and qualified, the experiences of having needs and receiving support to meet them is a part of a life experience. To provide a person-centred experience, the process must be governed by policy that is itself structured in response to an understanding of the experiences of those who have care needs and receive support provision.

Although policy indicates that support provision should be based on an individual's understanding and definition of their own care needs (*National Service Framework for Older People* (st2) DH 2001a, *Better Health in Old Age* DH 2004b, *A New Ambition for Old Age* DH 2006a) many older people experience a gap between policy intention and the realities of accessing support. It is necessary therefore to explore older peoples' experiences to understand more fully the factors within the relations of care that shape them; to establish whether the discharge process provides older people with feelings of autonomy and control over the risks assessed and the subsequent arrangements made for their return home; and to explore the levels of consultation, negotiation and empowering

support available to those returning home, both in the event of discharge and in the day-to-day experience of receiving planned support.

I aim, therefore, to extend the expression of policy aims above (see Figure 1.1) and develop a model that allows some analysis of the experiences of older people returning home as they move from acute care to the support of community health and social services. To do this, the main themes discussed by older people being discharged will be identified through the analysis of unstructured interviews and field notes that focus on older people's discussion of their experiences as they cross certain boundaries, both conceptual and physical, as people move from hospital to home, acute to chronic, from largely formal to largely informal, health to social care and from 'medical' to 'other'.

Returning home from hospital represents a stressful time for older people as complex negotiations in relation to quality of life, the future, morbidity and mortality are managed by those convalescing within an atmosphere of change and uncertainty. By drawing out the main themes a model can be developed that identifies the process of being discharged home and highlights the barriers and facilitating factors related to this process. In Chapter Two the political, economic and cultural societal forces that structure older people's health and social care experiences are explored by investigating the macro-power dynamics that produce gaps between policy and experience as evidenced in the literature. Policy governing older people's services and the structural forces that influence the implementation in practice of these services will be considered and the impact these dynamics have on older people in their experiences of care planning and

support consumption will be discussed. Chapter Two, although developed after concurrent data collection and data analysis was complete, is presented towards the beginning of the thesis in order to provide a background understanding of the research area.

Chapter Three discusses the methodological approach used to explore these issues, presenting a description and critical analysis of the grounded research process used in this project and provides an explanation of the analysis process.

Introductions to the individuals taking part in the project are also made in an attempt to maintain the context of individual experiences.

Chapter Four presents substantive (open) coding, the initial level of data analysis, and identifies individual experiences within which fractures in the links between policy and the lived experience must be managed on a daily basis. Each of the four main categories that emerge from this level of analysis, Making Decisions, Feelings of Independence, Matters of Concern and Managing Change, are composed of 'experience codes'; that is, experiences discussed by older people during unstructured interviewing. To move the analysis forward, the conclusion to Chapter Four presents a second aspect of open (substantive) coding as the dimension of the categories are defined and the experience codes are identified by a particular set of properties that exist along these dimensions.

Chapter Five completes the analysis through substantive coding, providing a fuller definition of the dimensions within emerging categories and a tentative model of the relationships existing between these categories. By organising the data in

respect to the emerging central ‘story’, Chapter Five also presents the final level of analysis possible here, theoretical (selective) coding, where the core category, *Managing Change*, is defined by exploring relationships between the categories that emerged during substantive coding.

Finally, Chapter Six provides a conclusion to the thesis, identifying findings and relating these to policy recommendations. In addition, the model arising from this analysis is considered in relation to issues of rigour, fit, grab, workability and modifiability. Future research opportunities are also discussed. Having identified the aims and provided a brief outline of the structure and purpose of this research, it is necessary to look in more detail at the literature which discusses societal forces that contribute to the gap between policy aims and their enactment.

1.4 Declaring on Interest

However, before I begin to discuss this range of contextual issues it is important to state my interest in this field of research and identify my ‘positionality’ in relation to the research question.

I trained as a nurse at a large London Teaching hospital during the 1980s and therefore learnt the nursing process (Roper *et al.* 1980), a then new patient-centred approach to providing nursing support and managing ‘hand-over’. It was with this tradition programmed into me through training, working as a staff nurse and training junior nurses that I ‘Returned to Nursing’ following the completion of my Sociology and Social Anthropology undergraduate degree in 2000. As part of this training course I worked as an auxiliary on the Department for the Medical

Elderly, and later as a Grade D staff nurse. The central part of my role was to provide nursing care for older women on the ward.

Differences between the practiced reality and theory of training were immediately apparent, for example, task-oriented nursing, such as 'back rounds', were still used on the ward; a method of care giving that I had heard of in respect to 'how things used to be done'. In addition, individual older people's privacy was often not protected and conversations between nurses during care-giving that excluded the patient were common-place. It was in this context, during the 2001 general election, that I asked the charge nurse what arrangements had been made for the older women on the ward to vote, and was dismissed with 'We don't bother about that'.

This exchange started me thinking about how much control the older people on the ward had over the care they received. During my work experience as an auxiliary nurse, and later as a staff nurse, I began to ask questions of the other staff nurses in relation to how much say older people had about their care. Some agreed that older people were not consulted or given the full information they needed to make decisions about going home and the associated support arrangements. As a result older women preparing to go home following a period of time in hospital did not have access to the empowering care, non-ageist attitudes or respectful relations of care that government policy promised and professional codes required.

After a number of problematic incidents where older people's views were overruled by the trained staff working with them without explanation, I felt that to stay

and try to nurse in this context would work against the NMC ethical codes of practice. It was at this point that I decided to leave nursing and work towards a theoretically based understanding of the most complicated of procedures on the DME, achieving a 'good' hospital discharge. I therefore have an experienced-based interest in how hospital discharge for older people is achieved, but more specifically in the power dynamics that attend every interaction between people in relation to care giving and receiving.

At the start of this project I was interested in the then new Single Assessment Process that was due to be implemented as part of the *National Service Framework for Older People* (DH 2001a). One reason for this was that the NSF for Older People promised person-centred, needs-led support that had been noticeable by its absence during my recent nursing experiences. A second reason was related to the gap between policy and practice that I had previously been aware of, and this increased my interest in observing the implementation of such an important piece of policy. A third point of interest was from a professional view, as the ethical issues that underpinned the NSF for Older People reflected professional ethical codes (NMC 2002) and had implications for professional practice.

However, during the negotiation of access when I discussed my research proposal with other professionals, and the initial period of observations on the wards where I was able to talk to staff nurses on a more informal basis, it became apparent that the SAP was not going to be introduced until April 2004, which was after I had planned to complete my fieldwork. In addition, a discussion with the Lead for

Implementing the SAP made it clear to me that the concepts underpinning SAP were already considered to be in place, and reflected 'best practice'.

Once fieldwork started, I also became aware that my research interest lay in the experiences of older people during the discharge process rather than how policy was implemented. Starting with older people's experiences seemed a more logical way of understanding what shapes their lives than starting with an analysis of the policy. In other words, my interest in the experiences of older people became central and issues of policy became more peripheral. This process continued throughout the project and this process moved the focus of this project from a concern with implementing the SAP to a broader consideration of how older people 'manage change' within acute health care encounters and subsequent transitions.

Therefore my research question developed as the concurrent data collection and analysis developed. The research focus changed from an interest in the implementation of the SAP to an exploration of older people's experiences of leaving hospital and returning home and how this related to older people 'managing change'. The processes of constant comparison and iterative analysis therefore started as soon as the project was conceived (Strauss and Corbin 1990). Having concluded this chapter with an outline of my personal position in the research, I will now move on to a consideration of the research area.

CHAPTER TWO

MIND THE GAP: A REVIEW OF THE CONTEXT

Developing a model that allows us to explore older people's experiences of leaving hospital and returning home enables an evaluation of, and a point of critique for, central government health and social care policy. Policy governing the support of older people tends to present the processes of assessment, care-package construction and discharge from hospital to home as a service that is user-led in collaboration with staff; needs-led including a responsiveness to older people's changing needs; and 'holistic' in terms of providing a 'seamless service' between health and social care agencies (*National Service Framework for Older People* DH 2001a). However policy intentions do not always translate to policy outcomes (Comes and Clough 2004) and this makes exploring the experiences of older people accessing support all the more important.

The notion of a 'user-led' service, where older people's decisions are central to care planning whilst supported in their decision-making by professionals acting as 'advisors', is explored in *Making Decisions* (see Section 4.1). For older people it can be argued that support provision is, at times, 'institution-led'. Policy that conceives of a hospital discharge process that puts the individual at the core and the multidisciplinary team as supportive and collaborative is not necessarily experienced as such by older people. Multidisciplinary case conferences, for example, are led by the medical consultant, other disciplines work in response and

secondarily to the medical lead; support at home is not arranged until the patient is medically discharged (Katz 1996, Latimer 1998, Moats 2006).

The notion of 'needs-led' support provision sees older people's needs as self-defined and central to the structuring of support once home (DH 2002a, 2002b, 2004b, 2006a, 2006b). However, older people are not always supported in their expression of self-defined needs and support is planned in response to professional agendas with reference to accessible resources. This leaves carers and older people to adapt and manage their needs in response to what support is available (Latimer 1998, Aronson 2002). Support provision can then be seen as 'resource-led'. Policy states that support at home must be responsive to changes in patients'/clients' needs (DH 2002a, 2004b, 2006a). However, this is not experienced universally; access and referral to support agencies is often confusing and complex for older people with changing needs (JRF 2004) leaving them and their carers unsure of where to get formal or professional help as their situation and condition alters once home. Furthermore, the aim to provide a 'seamless' service for older people moving from hospital to home (DH 2002a, 2002b, 2004b, 2006a) is not experienced by all older people (Age Concern 2003, Help the Aged 2002, 2009, JRF 2004, Dunning 2005). Analysis exposes a disjuncture that still exists during the 'event' of discharge between medically focussed hospital care and 'socially' focussed support provided at home (Latimer 1998).

It is important to acknowledge the gaps between outcomes envisaged when policy is written and how the implementation of this policy is experienced as it advances the project to provide a holistic experience for older people. The gaps between

policy intentions and policy outcomes are patterned by three central structural forces discussed in academic debate and evident in relevant policy, namely: the process of policy formation and implementation, both at a local level and within the practice of formal workers who support older people; economic interests and issues of funding and cultural issues including ageism, sexism and professional conflicts within health and social care. These three forces will be discussed in turn.

2.1 Policy production, implementation and practice

There is a theoretical gap in policy formation, between experience in reality and the research findings upon which 'evidence-based' policy relies. This calls into question the 'evidence' upon which policy is based and raises epistemological and ontological questions in terms of the extent to which research findings reflect reality. Care needs are met through formal and informal support, co-ordinated by health and social care professionals; national policy and how it is locally implemented, shape both the types of formal provision available and the overall co-ordination of support. Policy is used to target and ration resources to provide appropriate support within limited financial means. Political decisions guide how these funds are defined and distributed.

It is necessary to explore the links between the lived experience of being an older service user, the policy that governs this and the professional practice this informs for two main reasons. Firstly older people do not always experience flexible user-led access to the support they feel they need (JRF 2004, Dunning 2005, Age Concern 2007). Exploring the way research, policy and practice are structured and inter-related may go some way to explaining why this is the case.

Secondly, the notion that once research has informed policy, appropriate implementation and evidence-based practice are close behind and therefore the benefits of a more enlightened policy for older people (DH 2001a, 2001c, 2001d, 2001e) will be experienced by those in receipt of support can be problematised. This assumes a linear, 'cause and effect' model of the implementation of social policy that does not always occur (Cilliers 1998, Elliot and Kiel 1997). The implementation of policy does not always result in the initial desired effect (Cornes and Clough 2004). Therefore to understand the complex impact of enacted policies on the experiences of older people in their own homes we must look more closely at the way policy is constructed and implemented (Cornes and Clough 2004).

2.1.1 Policy Production

2.1.1.1 From experience to research findings

There is a gap between 'the lived life' and how research understands and interprets it that questions the accuracy of research methodology in describing 'reality'. Quantitative research methodology, favoured traditionally by bureaucracies such as the NHS, seeks to present itself as 'value neutral' and its research findings as 'scientific fact'. Within qualitative methodologies it is seen as impossible to remove the point of view of the researcher from the research (Darlington and Scott 2002). Collecting data and analysing is not a neutral process that gives results that can be presented as facts. The individual context of the researcher "permeates all parts of the qualitative research process" (Darlington and Scott 2002:18). This is apparent in the formation of the research question, the choice of methodology, the practical manner in which the data are collected, the analysis of collected data

and the way findings are presented and disseminated (Steadman 1991, Dey 1993).

This issue of researcher positionality is discussed in detail in Chapter Three.

The production of 'evidence-based' policy and practice depends upon knowledge available to those making policy and therefore upon findings produced during research. However, the production of research findings is not neutral and the process of research funding determines what knowledge is available to policy makers and is shaped both by what research commissioners view as appropriate and the selection process. The inclusion of 'service users' in the commissioning of research is essential to increase the production of research that can inform genuinely user-led policy (Glasby 2005).

Expectations of the academic world with regards to appropriate areas of research and standards of research are also of relevance. Research is managed by strict guidelines, such as the *Code of Ethics for Social Work and Social Care Research* (Butler 2002), *Research Governance Framework for Health and Social Care* (DH 2001b), and those within professional research bodies such as the *British Sociological Association's Statement of Ethical Practice* (BSA 2002). These codes ensure that appropriate research is ethically conducted. Researchers wishing to work within health and social care must get permission to research from the Health and Social Care Ethics Committee; research undertaken through a University must have ethical clearing. These codes are essential to ensure that participants are not exploited, ethical issues are addressed and the structure of proposed research is logical and methodical. However, they may be restrictive of innovative ideas and this will impact on the types of research undertaken.

User involvement in the production of research findings is essential to produce knowledge about the real lived experience of support that older people receive as service users (JRF 2004). This includes consultation with regards to commissioning research, types of methodologies used and the authenticity of findings produced through research that both informs and evaluates policy.

2.1.1.2 From research findings to national policy

In the construction of health and social care policy, research is used to provide an evidence-base; a process that is seen as ‘best practice’. However, the choice of which research findings are used in policy formation is a matter of political preference. Policy is produced within each government term in a way that reflects the political ideologies of those in power. Each instance of social policy is constituted by political ideologies and attitudes that reflect a certain historical ‘paradigm of thought’ (Illich 1976, Powell and Biggs 2003). Only certain research is referred to. These choices are not neutral, or without cultural, social, economic and political patterning, but are a reflection of political attitudes of the party in power and of the dominant discourses in society in relation to what is culturally acceptable or understood (Powell and Biggs 2003). The impact of underlying political ideology on the formation of health and social care policy can be seen in two linked ways: in the different approaches of changing governments and in the increased inclusion of consumerist notions in the health and social care policy that governs older people’s care.

The NHS and the idea of centrally provided support for all those in need grew out of the social cohesion evident at the end of World War II (Thane 1996). The political ideology underlying its conception was the support of the vulnerable by

the working majority. The initial structure of the NHS reflects the political paradigm of social welfare that is state funded, universal and provided to those in need.

At the time of the implementation of the *National Health Service and Community Care Act* (1990) the political ideology of the New Right government saw people as economically competing 'individuals'. Prime Minister Margaret Thatcher, talking to *Woman's Own* magazine, stated 'there is no such thing as society' (October 31 1987). The 'individual' was seen as responsible where possible for their own provision. The 'internal market' was introduced into both the social services and the NHS, and the means test was strengthened. This was to promote market principles and competition with the aim of raising standards in hospitals and community care. Older people with long term support needs were moved out of hospital 'into the community', increasing 'the market' for domiciliary care, nursing and residential homes.

New Labour social policy presents the individual as having both rights and responsibilities in relation to the community. Consumerist and communitarian ideals are incorporated within the 'Third Way' approach to support provision which, some argue, continue neo-liberal themes (Ferguson 2007).

How older people negotiate consumerist ideals implicit in policy aims can be seen in their experiences of the discharge process. In preparation for the return home, detailed assessment of medical, nursing and social care needs is essential to identify potential risks and provide an appropriate package of care. Traditionally,

separate assessments were made by professional groups such as medical and nursing staff, physiotherapists, occupational therapists, both ward and community social workers and members of the primary care trusts, such as community nurses and community mental health nurses. However, this method of preparing discharge packages was criticised (Richards 2000, DH 2002a, 2002b, Chevannes 2002). First, in this traditional model the wishes of the service user, the older person, are not at the centre of planning so that the concerns and practicalities faced by service providers limit discussion surrounding possible health and social care support (Daly 2001). Secondly, following from this, these traditional methods of assessment represent an invasion of privacy, as areas of concern represent professional agenda rather than those of the individual and family (Richards 2000, Wenger and Tucker 2002). Thirdly, separate forms of assessment led to repetitions, omissions and misunderstandings between those involved in planning care (Nolan 2000).

The NHS Plan (DH 2000a), the National Service Framework for Older People (DH 2001a, 2004b, 2006a) and the Single Assessment Process (DH 2002a) aimed to introduce an assessment process with a holistic approach to the discharge process to ensure older people are able to take a proactive role in preparing for home (DH 2001a). Co-ordination of assessment and discharge planning are now managed through multi-disciplinary assessment procedures and team case conferences, where all those involved in the support of an individual, including the individual, carers and family, contribute to assessments made and planning the practicalities of returning home.

The impact of political ideologies on the health and social care of older people can be seen in the disadvantages this group face as a result of the increasing influence of consumerist ideals into health and social policy in general and care of older people during the discharge process in particular. The impact of central concepts apparent in consumerist approaches, namely: participation, choice, holism, independence and equality of opportunity, are evident within policy that governs the discharge of older people.

There has been a shift in the way the relationship between the individual and the state is conceptualised; a move away from the state welfare model, where the state is seen as responsible, towards a mixed welfare model, where participation by the individual and their families in managing their own health and social care welfare has a central role (Waters *et al.* 2001, Walker *et al.* 2007). Alongside this is the debate that surrounds the New Labour's Third Way, which focuses on finding a balance between the rights and responsibilities of a citizen. Although we have the right to care and support when we need it, we have the responsibility to make healthy lifestyle choices and to be an active citizen in the provision of services. From being individually responsible for our health and well-being to taking part in local consultations, the concept of 'participation' is fundamental to current health and social care policy. The importance of participation is also evident within the mechanism of person-centred care (DH 2001a, 2002a, 2002b), which places the service user at the centre of discharge planning. In the promotion of 'user-led assessment', potential problems, as defined by the older person, become central to the assessment process that structures support (Ungar 2001). This may firstly avoid the unnecessary invasion of privacy apparent when service provider agendas

are followed (Nolan 2000), and secondly empower the older person by allowing them a central role in defining problems and in planning their own lives after hospital care (Nolan 2000). In reality however, assessment of the older person in preparation for discharge from hospital to home and community care necessarily represents a negotiation of professionally defined 'risk' between professional health care disciplines, the individual and the family and/or carers (Shaw and Shaw 2001).

The ideal of the individual in general and in relation to health and social care support in particular has also changed. Traditional conceptualisations of the 'good patient' saw a passive individual that fulfilled certain expected roles including compliance with medical advice (Parsons 1951). Consumerist notions see the individual in a pro-active role, with access to 'choice' (Ferguson 2007). This can be seen in policy where there is a focus on the individual being able to make choices about the definition of needs in the assessment process and decision-making in the planning for discharge (DH 2001a, 2002a, 2002b, 2003c). Thirdly, recommending the implementation of a 'needs-led' approach to the provision of person-centred care during the discharge process aims to increase choice and reduce the imposition of professionally defined categories. Furthermore, discharge from an acute hospital setting to home can be seen as a highly individual affair, patterned by both the structural restraints of finance and real life practicalities, as well as personal and individual concerns, such as an awareness of the condition and an understanding of how this may have an impact upon the ability to 'carry on as before', individual character, past experience and hopes for the future. Discharge from hospital to 'home' therefore can differ widely from person to

person and must be responsive to individual needs and wishes. Person-centred care is the mechanism by which policy aims to make the planning and structure of older people's care individualised and participatory (DH 2001a).

The centrality of the individual is further exemplified in the aim for holism. Policy aims to ensure 'joined up' and 'seamless' services in order to provide consumer/service user focussed provision; the individual is the starting point for the definition of needs and the identification of appropriate support. The use of an holistic assessment outlined in the *Single Assessment Process* (SAP) (DH 2001a, 2002a) acknowledges the fact that the 'needs' of an older person do not recognise professional boundaries (Dalley 2000, DH 2001a, 2002a). That is, services may be defined and financed, as health or social care, but meeting the needs of older people requires a complex and dynamic relationship between all professional bodies. Changing attitudes towards older people in the NHS is apparent within the National Service Framework for this group, where a single assessment process reflects the need for increased co-ordination between those assessing an individual in the preparation for discharge home. However, implementation of the SAP (DH 2002a, 2002b) is mediated locally and Trusts are given scope for implementing the principles within their area.

The aim of discharge policy and the assessment and planning of help is to support older people in the maintenance of their independence, so ensuring a good 'quality of life', understood on the basis of subjective definition. The notion of the 'independent individual' is central to consumerist conceptions of the individual and there is a move away from 'doing to' and towards 'doing with' in the

management of the discharge process and care-giving (McCormack 2001), and in the co-production of support planning (Dunning 2005, Lloyd 2006, Tanner 2007). New Labour policy seemingly reflects enlightened notions of care for the older person in his or her own home, aiming to enable those who still have the independence to 'manage' for themselves on the understanding that maintaining independence and control over one's own life, in one's own familiar environment lengthens life, or at least is seen to represent a 'quality of life' (DH 2002a, 2003c, 2005a). These assumptions, that home care is the most appropriate and enables individualised support, have been criticised (Dunning 2005) and the need to consult older people in discharge planning and evaluation of the support package has been highlighted as central to the provision of appropriate and respectful support (Lloyd 2006, Tanner 2007)

Equality of opportunity is also a central concept of consumerism and is evident in New Labour health and social care policy governing the planning and support available to older people going home from hospital. Everyone in need will have those needs assessed, and through the provision of medical support free at the point of delivery and social support as targeted through means testing, all older people have access to an equal opportunity to have their needs met, depending on levels and types of needs and circumstances. Care, treatment and support are provided therefore on the basis of need rather than on the basis of age.

Concerns with equality of opportunity therefore are evident in the focus on 'tackling ageism': the aim is to reduce discrimination within the National Health Service (NHS) in relation to age (*National Service Framework for Older People*

DH 2001a). Tackling ageism within the NHS necessarily requires a conceptual shift from those working within care services through a personal analysis of attitudes towards people based on age (Golden and Sonneborn 1998). As policy demands equality within the service, it is hoped practice will follow. However, understandings of older age are socially constructed and culturally contextual, not objective and universal (Chevannes 2002) and personal attitudes of professionals that frame the older person as dependent and childlike may continue to impact on assessment (Golden and Sonneborn 1998, Nolan 2000, Chevannes 2002), for example, in questioning an individual's ability to manage situations that they themselves may not define as problematic. Notions of the older person as 'vulnerable' may lead to bias towards a professional agenda and the importance of fulfilling service requirements to protect against potential risk (Nolan 2000).

User involvement

It is important to note the impact of both user involvement and consultation in the development and implementation of health and social care policy with regard to the support of older people in their own homes after they have left acute care. *The NHS Plan* (DH 2000a, 2004a) and the associated *National Service Framework for Older People* (DH 2001a, 2004b) both require the involvement and consultation of the user and professional bodies. This is a mechanism to ensure policies are responsive to the changing needs of the service users. If, through user consultation during research, user involvement in research commissioning and the use of methodologies that are user-view inclusive, research is produced that represents user-led concerns alongside professional concerns (JRF 2004), then when this research reaches the stage of being included in policy making, it can no longer be considered as 'user-led' if it is not economically or politically expedient to

implement findings. The example of free personal care is relevant here (Sutherland 1999). It is of concern to those service users that have been consulted that personal care in England and Wales is subject to a means test through the eligibility criteria which varies between regions. Free personal care is also a point of campaign for older people's representatives (Age Concern, Help the Aged) and although personal care is free in Scotland, it remains means tested in England and Wales. This does not represent a service that considers the views of the older people using it.

2.1.2 Implementation of national policy at a local level

2.1.2.1 Regional Variations

National policy with regards to health and social care is locally implemented. For example, each NHS Trust is responsible for the implementation of the SAP in their own area; Primary Care Trusts (PCTs) have a budget to provide health care needs in their area. Councils set a social care budget for the locale, which is targeted on those in financial need through the 'eligibility criteria', which are interpreted and implemented at a local level. However, while this has the advantage of being responsive to local needs and concerns, it also leads to older people in different parts of the country having differing access to free support, whether it be medical and health related ('post code health lottery') or home support services and associated with what is regarded as 'social needs', due to differences in severity of the eligibility criteria (Katbamna *et al.* 2002). The *National Service Framework for Older People* (DH 2001a) was established to allow local flexibility whilst maintaining national standards; however, regional variations still remain.

2.1.2.2 Central Control

Local funding gives the appearance of freedom to allocate local funds as locally appropriate, however, the bench marks and targets set by the New Labour government can be seen to undermine this local democracy and indeed control the provision of health and social care from central government. Targets have become the central goal in some cases, as illustrated by the government realisation that targets were too restrictive (Blair *PM* BBC Radio 4), the case of NHS Managers ‘manipulating’ the A&E waiting times to meet targets (Shannon 2004) and concerns surrounding the ‘tick box’ culture of New Labour (Dalley 2000).

Policy implementation, that is the manner in which policy is used by the local health and social care institutions, can be seen as part of policy making itself (Cornes and Clough 2004) as it has a significant impact on how policy works on the ground and is experienced by service users. However, the implementation of policy does not always result in the initial desired effect (Cornes and Clough 2004, Glasby 2005) and may be shaped by local political or financial concerns.

2.1.3 Formal practice

2.1.3.1 Evidence-based practice

One area in which national and local health policy impacts on older people’s experiences of accessing support is through evidence-based practice (Rydeman and Törnqvist 2006, Walker *et al.* 2007). This is necessarily informed by current research that may contain biases and assumptions. For practice to be truly ‘evidence-based’, appropriate training is required to enable professionals to evaluate and interpret research. However, this is also true of any formal carer providing care to older people and therefore training should include care assistants and other providers of formal support. Access to training, regular updates and

career development is essential if high standards of care are to be made available to older people living in their own homes.

2.1.3.2 Codes of conduct

Codes of conduct, hospital protocols and conditions of employment also represent a point at which policy informs and shapes practice. They provide ethical guidelines for the care and support of older people by formal staff, to protect individuals from harmful care and to maintain the care value base (Nursing and Midwifery Council 2002, General Medical Council 2001, British Association of Social Workers 2002, General Social Care Council 2002, 2004). However these guidelines can also work to reduce professional autonomy which allows health and social care workers to make decisions that are responsive to older people's self-defined needs (Taylor and Donnelly 2006). Furthermore, a culture of working to high professional standards, regulation of care staff and enforcement of the codes of conduct are necessary procedures to ensure these codes are enacted in practice (Atwal 2002, Huby *et al.* 2004, Jordan 2004, Dunning 2005).

2.1.3.3 Practice in 'the moment'

Without training and a reflective approach to carrying out informed practice, issues of culture and tradition can arise and shape practice and increase the risk of a less enlightened approach within the relationship between the individual and the carer. Some studies report that older people's contributions to care planning are 'not heard' (Waters *et al.* 2001, JRF 2004, Raynes *et al.* 2005, Doherty and Doherty 2005) reflecting a dynamic where their opinions are not, as is stated in policy, effectively central. Therefore, to ensure high standards and an implementation of evidence-based policy through practice, caring for older people must be seen as 'skilled' work that requires appropriate levels of education that

include practice reflection, a critical understanding of research and ethical training (Lloyd 2006).

The *National Service Framework for Older People* documents the policy plan for services that are provided to older people (DH 2001a, 2006a). It advocates zero tolerance on ageism, the centrality of an individual's needs in assessment and support planning requiring the empowerment of the individual in autonomous decision-making and putting the individual at the heart of care planning and support provision. Although this does reflect a paradigm shift in terms of institutional attitudes and a reflective review of assumptions made about older service users, the challenge is to bring these new enlightened attitudes to the planning of care strategies for individual recipients of support provision. An analysis of policy that aims to support older people must include the experience of older people themselves (DH 2001b, 2004b). Furthermore, ethical practice in organising discharge and the return home has to include respectful relationships between older individuals and skilled carers. National and local policies, as well as codes of conduct impact on the practice of individual formal carers. How the older person experiences the upshot of this regulation in the moment of practice must be compared to the intentions of the policy.

A successful discharge plan is not only based upon an individual's self-defined needs and how they currently manage their needs (Lloyd 2006), but also builds upon how older people manage well being and health and develop strategies for managing their lives (Powell *et al.* 2007). To provide this type of person-centred and holistic care, it is necessary that the implementation of policy is effective.

However, there are a number of issues surrounding the implementation of policy in practice that disrupts policy aims and does not produce the required outcomes.

First, there is the practical problem of implementing policy that arises if there is not an indication within policy documents that suggests how to enact all of its aims. The implementation of *Delayed Discharges* (DH 1996, 2003c) can be seen as an example of this as putting the policy into practice was compromised by local differences and complicated by the impact of available service provision (Glasby 2003b). Furthermore, although the aim of anti-ageism is implicit in policy discourse, there is no explanation of how to do this in daily practice (Roberts *et al.* 2002). A further issue that impacts on the effectiveness of policy implementation in achieving policy aims is the unintended consequences of performance measurement (Holloway and Lymbery 2007), that is, practice reflects the need to complete or comply with central and local governmental targets and is not driven by the immediate needs of individual service users. The agency perspective then still dominates (Tanner 2003, Lymbery 2005).

Secondly, current policy impacts on the working practices of staff. Professionals, for example, nurses and social workers (Holloway and Lymbery 2007) agree with the aims of policy that puts the individual as central to the management and planning of their own care but remain unclear about how to meet these in practice (Beresford *et al.* 2007 cited in Holloway and Lymbery 2007: 376). Furthermore, the standardization of practice and imposition of procedural rules leads to a tension between ethical values and the daily practice context in which professional

care workers operate (Lloyd 2006:1172). However Lymbery (2005) asserts that it is possible to practice professional methods in a managerial framework.

The implementation in practice of current policy that structures care and support for older people managing the changes involved in hospital discharge and the changes experienced once home, raises a further professional concern. It represents a potential threat to skills levels amongst practicing professionals by changing the role of the professionally qualified practitioner from a 'do-er' and enactor of care to an 'overseer' and manager of care; this is further exacerbated by a concern with increasing access by providing advice through call centres and NHS direct (Ferguson 2007), a source of contact not readily available to all those who are receiving support at home.

Deskilling leads to problems associated with a lack of advocacy understanding by those providing formal semi-professional support. Access to these skills is essential in the implementation of policy in day-to-day relationships in which changes to needs are managed and met through changes to support. These skills are also needed in the identification and referral required to meet larger scale changes that may impact on the structure of the support received once home.

Central to the implementation of policy is the skilled practice of those who support older people through their assessment of needs and in the structuring of the care plan, and those who provide support with managing changing needs once home from hospital. Effective communication is vital if older people are going to experience person-centred care where they lead both the definition of need and the

construction of support available to ‘co-produce’ an effective and viable care plan/pathway (Lloyd 2006).

Communication within the multidisciplinary team (MDT) is key in effective discharge (Atwal 2002, Bowles *et al.* 2003, Preen *et al.* 2005, Bolch *et al.* 2005). However the *Single Assessment Process* (DH 2002a, 2002b) is proving difficult to implement in practice due to the presence of different professional cultures and work practices within the MDT (Dalley 2000, Brown 2003), and the differing time and resource restrictions each professional group faces (Bowles *et al.* 2003); lack of time (Atwal 2002) and a competition over resources reduces the effectiveness of inter-professional working. The MDT includes, in theory, the individual older person and their carer (as relevant); for communication to be effective it should include them all in practice (Walker *et al.* 2007).

Central to the dynamic between members of this MDT is the relationship older people have with formal sources of support, especially those professional health care and social support workers that work with them to structure a care plan/pathway for their return home. Unless older people have a voice in the planning and management of changes in their support needs, the work done by professionals is ungrounded (Walker *et al.* 2007). The way in which personnel relate to older people determines how much older people participate in the planning of their care and in what way they take part (Gustafsson 2004); language and disposition of staff effect how older people see themselves and behave (construct themselves) (Minichiello *et al.* 2000), especially as needs are defined, in part, through the language used to define them (Parton 2003, Sevenhuijsen 1998

cited in Lloyd 2006:1172). However, older people are still not able to express themselves and staff are not trusting of their competence to manage (Huby *et al.* 2004)

2.2 Economic interests and issues of funding

Public issues at a macro-level are directly related to and shape day-to-day experiences (Mills 1959, Bourdieu 1973, Bourdieu, and Passeron, 1977) of those receiving support for their care needs (Powell and Biggs 2003, Glasby 2005).

Levels of health and social care funding, what these resources are spent on and the mechanisms for distributing these resources impact on the levels of skilled practice, the range of support alternatives and opportunities for older people to take part in autonomous decision-making about how they are to manage their care needs in daily life.

Economic interests structure social institutions (Marx 1859) and this is true for institutions that provide support for older people. Therefore economic interests define in part the care experience of the individual and can work against the policy aims of person-centred care and a ‘seamless service’ that are central to the ethos of ‘choice’. Despite, therefore, the political will to provide care that is unified and ‘seamless’ (DH 2001a), the division between health and social care is maintained, in part, by economic issues. This is apparent on two levels; firstly, in the structuring of institutions by the economic interests of both the pharmaceutical and medical industries and secondly, in funding structures that are used in the financing of health and social care support. These interests represent a factor in explaining why the provision laid out in policy is not always experienced as intended.

2.2.1 Economic interests and the health-social care divide

A holistic approach by health and social care support providers is necessary for older people to receive appropriate support during the discharge process of preparation for home, in getting home and in being at home (DH 2001a). The importance of collaborative working is acknowledged in policy: in the *NHS Plan* (DH 2000a, 2004a), the *National Service Framework for Older People* (2001a, 2006a), the resultant implementation of the Single Assessment Process (SAP) and the structure of Primary Care Trusts which require a multi-disciplinary team approach to care and the promotion of 'joined-up' commissioning of services. However, economic interests are fundamental to the structuring of social institutions (Marx 1859); this can be seen within the institutions that provide support for older people (Katz, 1996, 2000, Powell 2001, Powers 2003). Where policy aims to bridge the gap between health and social care, the primacy of the biomedical model maintains this division as it reflects and serves the economic interests of both the medical industry that represents health professionals and pharmaceutical companies that produce treatments at a profit.

2.2.1.1 Primacy of the Biomedical model

Biomedicine is the main belief system which dominates current formal understandings of health and illness. It privileges the Cartesian dualism over a holistic approach within the opposition of mind versus body (Turner 1992). It sees the seat of its praxis as the physical body in general and the site of illness in particular. The body, therefore, is of primary concern to the practicing physician and it is the focus of the medical view (Foucault 1973). It is seen as functioning detached from the mind within, as a logical system that can be investigated and understood through a positivist approach.

Biomedicine has been criticised for representing a system of thought that relies on modernist, mechanical notions (Turner 1992) where the mind and body are conceived of as separate and the body is seen as a mechanism (Turner 1992:139) that can be fixed through invasive 'treatment' (Illich 1976); as an object that behaves in a predictable and generalisable manner, rather than the lived, subjective experience of being conscious within the physical skin.

The dominance of focus on the body by medical practitioners and the medical industry in general, has been challenged from a number of views, including political and academic deconstruction by those who see biomedicine as a system of social control (Foucault 1973, 1980, Illich 1976, Martin 1989, Katz 1996, Powers 2003, Powell and Biggs 2003), by feminists who analyse biomedical action as an expression of patriarchal domination (Martin 1989) and by postmodernists who conceptualise the body as a lived category and therefore a whole that cannot be reduced (Turner 1992, Shilling 1993, Nettleton and Watson 1998).

Practice, research and biomedical knowledge of mainstream medical professions largely maintain, integral within itself, this Cartesian dualism, identifying the body as the province of medicine. The epistemological assumption, that the body alone is the appropriate focus of biomedical interest, structures the institutions that provide support. The historical development of medicine and the later evolution of social care led to a system where different institutions provide different types of support, health care by the NHS and social care by the Local Authority (LA) social services. This runs parallel with the notion that all aspects that are not seen

as physically based are categorised as ‘other’ and seen as ‘social’ (Latimer 1998, Twigg 2002). Although policy moves have been made, such as including Health and Social Care under one umbrella and the establishments of multidisciplinary working through multi-disciplinary teams (MDTs) based at Primary Care Trusts, health and social care are still defined in terms of being ‘medical’ or ‘other’, reflecting the economic interests of professionals, pharmaceutical companies and the concomitant increasing medicalisation of living.

The structuring of institutions of support and the primacy of the biomedical model within this has a reflexive relationship: each justifying the structure, power base and function of the other. To understand the interests and factors that maintain this status quo (the primacy of the biomedical division between mind-body; the structure of support institutions that conceive of ‘medical problems’ and everything else as ‘other’ or ‘social’) it is necessary to look at the economic interests of those that benefit from this being so. A closer inspection of the relationship between funding of the NHS and the economic interests of pharmaceutical companies as well as other ‘winners’ in the medical industry is necessary, especially in terms of those who ‘have the ear’ of government and are able to bring their power to bear in the form of lobbying and therefore having their interests considered in the formation of policy.

2.2.1.2 Interests of Medical Professionals

Professional bodies, such as health and social care professionals have economic interests in maintaining the status quo as they make money from their biomedical knowledge (Foucault 1973, 1980, Illich 1976, Powers 2003, Powell and Biggs 2003). Their power base would be undermined if notions of health and illness, and

the links between mind and body, were fully explored. The advantage experienced by older people who have their problems defined as ‘medical’ as opposed to ‘social’ in the discharge from hospital to home has been highlighted (Latimer 1998, Twigg 2002) as those whose needs are defined as medical have access to care that is free at the point of delivery and, as medical care is privileged over social care, have priority given to the meeting of these medically defined needs. This serves to emphasise how powerful the ‘medical’ is in defining and structuring support available to older people to meet their care needs once home.

2.2.1.3 Interests of Care Agencies

Some older people find formal support unsatisfactory and disrupted by the actions of domiciliary care agencies, such as home helps that do not arrive at a regular time, or changing home helps (Aronson 2002). These factors may reflect the interests of the private domiciliary care agency to maintain a profit margin (*Panorama: A Carer’s Story*, BBC 1 2003, *Panorama: Britain’s Homecare Scandal*, BBC 1 2009), leading to low levels of staff, high case loads for workers, the use of unqualified staff (as they are cheaper to employ) and tight work schedules. This leaves little flexibility and a limited skills base to respond to older people’s needs.

2.2.1.4 Interests of Pharmaceutical Companies

The hegemony (Gramsci 1971) of the biomedical view is maintained by the actions of those with economic interests in the status quo (Illich 1976). From this approach the NHS and Social Care services can be seen as structured in response to, and as a result of, the power exercised by pharmaceutical industries, that produce treatments, write research and medicalise problems thus ensuring an expanding market. A Commons enquiry, for example, accused Britain’s drug

industry of ‘disease-mongering’, of turning Britain into an over-medicalised society that believes in a ‘pill for every ill’, and creating ‘ills for every pill’ by inventing syndromes, such as mild depression in order to market a particular drug. The result is an over emphasis on medical solutions at the expense of cheaper, more effective therapies or prevention (Hinscliff 2005).

To support and increase the potential market medical knowledge must remain saleable and medical treatments invasive and externally provided through expert action. It is therefore in the pharmaceutical industry’s interest to maintain the mind-body ‘Cartesian’ dualism; this in turn reduces the effectiveness of progressive policy that aims at ‘holism’ and integration between health and social care institutions and practitioners.

2.2.1.5 Medicalisation

For the pharmaceutical industry, the NHS represents a lucrative market opportunity. Indeed concern is growing about the selling tactics that drug companies use both on individual doctors and the NHS as a whole (Moynihan *et al.* 2002, Williams 2007). Over the last one hundred years great (although decreasing) levels of trust have been placed on medical professionals and the cultural notion that there is ‘a cure’ feeds into patient expectations of the doctors whose help they seek. At the same time there has been an increase in medications accessible over the counter, a subsequent increase in advertising and a widening number of conditions for which medication is sought as a solution.

This increased availability of medicines, with their associated advertising, can be seen as expanding choice and autonomy in terms of accessing treatment for

problems, without the need to consult medical opinion. This may represent an empowerment of people from the monitoring of the medical professions or an enabling of self-help; the increased numbers of 'medical problems' for which there is medication available may appear as the progress of medical science. However, in reality this is not the case. We are, largely, offered few alternatives to the biomedical in times of extreme need. Despite some concessions and the consumerist power that has resulted in the rise in people consulting complementary therapies and using alternatives, the medical industry resists its inclusion. This can be seen in the extreme criticism of homeopathy from the medical establishment who cite poor research methods and theory use (Hunter 2002, Shang *et al.* 2005). However, the pharmaceutical industry itself is attracting increasing criticisms of the standard, reliability and validity of the medical research it produces (Young 2001, Bhattacharya 2003).

2.2.1.6 Impact on Older People receiving support

The continuing division between health and social care impacts on older people's daily lives in a number of ways. First, through the imposition of categories, during assessment, of needs as medical or social (Latimer 1998, Twigg 2002); health needs are supported free at the point of delivery while 'social needs' are means tested. Secondly, the presence of the health-social care division can produce an experience of fragmented and non-consultative support. Dislocation and conceptual differences between the two types of care response allow for miscommunication between the two approaches that can lead to a disempowering experience of support. Thirdly the division can lead to reduced access to non-medical definitions of care needs. The primacy of the medical power to categorise needs means that other potentially more appropriate approaches are overlooked.

Issues of safe medication for older people have been addressed through the *National Service Framework for Older People* (DH 2001a) and evaluation of the effectiveness of these increased controls remains on-going. However, for older people the increasing ‘medicalisation’ of old age (Moynihan and Smith 2002) represents certain risks, such as cascade prescribing (Rochon and Gurwitz 1997, Grant 2005) and the extension of invasive ‘treatment’ into problems that would not have been traditionally treated as medical issues (Moynihan *et al.* 2002, Hajjar *et al.* 2005).

Cascade prescribing has been seen as a problem for older people living at home. Cascade prescribing describes a situation where either an older person is given one tablet, that produces certain side effects, the symptoms of which are treated by further, different medication, again producing side effects, or the complex upshot of both drugs and the individual’s internal chemistry produce other unwanted effects, the symptoms of which are again ‘treated’ with further medication (Grant 2005, Hajjar *et al.* 2005). This situation can go on for a number of years, as older people’s medication is not necessarily reviewed in the whole, especially if they are travelling from hospital to home, between hospital doctors and their own GP, or more accurately, the GPs in the practice of which they are a patient. Each medical specialism may prescribe medication within the hospital and communication between hospital and GP surgery is not necessarily reliable.

2.2.2 Funding Structures

Historically, health and social care come from different roots, with different funding issues. Breaking the ‘Berlin wall’ between health and social care (Frank Dobson 1998 cited in DH 1998a: 1) is seen as a policy aim (DH 2000a, 2004a),

but policy decisions, based on notions of 'just' redistribution of resources, have restricted access for older people to free (at the point of use) personal care in England. Older people's needs are therefore politically defined at an individual level, as either medical and of health concern or 'social' and the responsibility of social care workers. This is especially true when related to decisions surrounding the redistribution of resources, as health care is free at the point of delivery and social care is means tested through the eligibility criteria. This distinction works to maintain divisions between support institutions and against policy aims of 'a seamless service' (DH 2000a, 2002a, 2004a).

At the 'providers level', antagonistic policies such as 'reimbursement' work to maintain the divide. 'Reimbursement' refers to health policy aimed to stop 'bed blocking' (Glasby 2005). Older people were remaining in hospital after they were medically recovered while awaiting support services or provision to be organised at home. In order to reduce the number of older people waiting to return home, the government introduced 'reimbursement', which defined the responsibility for medically discharged older people as belonging to social services (DH 2003b, 2003c) who were then required to pay for the bed place. The policy of reimbursement reflects the impact of funding issues on the dynamics between health and social care, as policy aims reflect a need to collaborate whereas funding issues produce an antagonistic relationship. Therefore, although policy posits an aim to provide person-centred, needs-led care, economic issues of finance and funding work against this aim and produce complex outcomes that do not necessarily represent the conditions most positive for the individual older people who would like to access or are currently accessing support services.

2.2.3 Personal Finances and Personal Economic Capital

Although those with high levels of economic capital and an effective command over economic resources (Bourdieu 1986), may be able to access care that is more comprehensive (Katbamna *et al.* 2002, Ferguson 2007), equality of care necessarily requires that a minimum standard of care is available to all those who need it irrespective of their financial position (DH 2000a, 2001a). Means testing as represented by the eligibility criteria, aims to target resources on those living on low incomes to ensure that an acceptable standard of care is provided for these individuals. However, concerns that means testing of personal care leads to personal anxieties have been growing (Sutherland 1999, Raynes *et al.* 2005, Dickinson *et al.* 2007); means tested provision can be seen as problematic when older people do not access the care they need due to concerns about the expense (Sutherland 1999, Harris 2003, Hill *et al.* 2007) and it results in the need to personally pay to meet the advice given by the doctor. Economic capital may lead to an increased autonomy in the consumption of support provision as capital enables an individual to 'choose', through 'buying in' support provision that matches care needs (Katbamna *et al.* 2002, Ferguson 2007).

Schemes that aim to provide older people with financial help towards organising support that suits their individual needs, condition and situation, for example the proposed voucher system (DH 2003a), are complicated and rely on the notion of the 'autonomous consumer'. This is an ideology of the 21st century; not necessarily one shared by those who were adults that took part in and experienced the social solidarity of the post war years. This cohort may have attitudes that reflect a time when ideas of co-operation were mainstream, when modernist notions promoted a certain unquestioning trust in the medical profession (Powell

and Biggs 2000, Powers 2003) and the concept of an appropriate 'sick role' was 'passive' (Parsons 1951). It was not the place of a 'good patient' to be knowledgeable about conditions and treatments. Now we live in a paradigm of 'the expert patient' (DH 2001f) where it is our duty, as a consumer, to take responsibility for our health through our lifestyle, through increased access to information from diverse sources and through the use of biomedical and complementary approaches as well as formal and informal sources. There has been a rise in the access to others in self-help and support groups via the internet and this has been encouraged through the idea of a health service that promotes health; reflecting a recent paradigm shift from a focus on 'cure' to prevention. It cannot be assumed that older people are accessing this type of support and information from the internet (Dunning 2005).

This represents a shift from an assumption that 'the doctor knows best' to 'doctor as advisor' within a more collaborative exploration of an individual's health support needs (DH 2001a, 2004a). However, it cannot be assumed that older people see things in the same way (Lloyd 2006). Although they do have experiential knowledge of the conditions that they are managing in the day-to-day, they do not necessarily understand the importance and validity of their own experience in the face of formal medical knowledge. Due to the individual nature of older people's understandings, they may not tell the doctor things that would help in the management of their condition; similarly they may not tell the nurse things that would help in the management of an effective discharge.

A number of questions arise from this discussion. Firstly, although the current ideological view of the adult individual, the active consumer of health and social care, may be expressed in policy documents and practice codes, protocols and guidelines, is this either the view or the experience of those who are receiving formal care and support? Secondly, are policy aims to provide autonomous and appropriate support tailored to the individual achieved through means tested provision? Thirdly, where individual autonomy cannot be directly enacted, do older people receive the professional advocacy necessary to put their self-defined needs at the heart of support planning irrespective of levels of personal economic capital?

2.3 Cultural issues of ageism, sexism and professional conflicts

Finally cultural issues, cultural differences and cultural misunderstandings such as stereotyping, both ageist and sexist, impact on the way in which and the extent to which support is provided for care needs. Cultural differences between professional groups in the new collaborative approach work against the provision of a seamless service through the multidisciplinary team.

2.3.1 Ageism

Older people's services suffer both in terms of the amount of resources and the associations of 'being old' with vulnerability and powerlessness (Hockey and James 1993, Lloyd 2006) that leave the care of older people out of the limelight. Service areas that are perceived as 'overlooked' have become known as 'Cinderella services' as they are seen as less interesting, less prestigious and less skilled than other possibly more 'exciting' disciplines, such as cardiac surgery or intensive care (Tronto 1993, Help the Aged 2006).

A culturally dominant focus on the young as the ideal state, and the stereotype of the older person as ‘dodderly’, dependent and draining of resources (Hockey and James 1993, Lloyd 2006) lead to possibly lower value being placed upon their needs. Older people’s place in society is further undermined by the cultural relation between older age and a less than full adult social identity (Hockey and James 1993, Lloyd 2006), which underlies ageism in contemporary society and culture. The effects of this are widespread for older people today and this is especially true when considering the return of older people from hospital to home.

A result of this cultural domination of ageist attitudes was less than respectful relationships between older people and their formal carers. However, since the introduction of the *NHS Plan* (DH 2000a) and the implementation through the *National Service Framework for Older People* (DH 2001a) a conscious policy aim has been full consultative and collaborative discharge planning using a Single Assessment Process, placing the service user at the heart of decision-making, not only as a user group in terms of policy formation and evaluation but in terms of the individual’s package of care on discharge home from hospital. A conscious aim to tackle ageism is noticeable not only at policy level but in terms of practice (General Medical Council 2001, Nursing and Midwifery Council 2002, British Association of Social Workers 2002, General Social Care Council 2002). There is a focus on patient-centred care and discharge planning, where full autonomy is supported through respectful relationships and the full provision of information necessary to making an informed decision and giving informed consent (*Data Protection Act 1998, Human Rights Act 1998*).

Trained staff, such as nurses, doctors, social workers and some care assistants receive 'ethical training' as part of their qualifications. This type of training, although vital in providing workers with skills to support an ethical and respectful relationship with older people and so enabling autonomy during decision-making, is not available or undertaken by all of those that support older people, many of whom are untrained or informal carers.

A shift in the role of health and social care professionals has led to a structure of home care where largely staff that have received a low level of training are providing 'hands on' support for older people and are managed and monitored by those who are professionally qualified (Waters *et al.* 2001) Without appropriate ethical training those providing this 'hands on' care can not necessarily understand the importance of spending time talking and listening to the older people with whom they are working. However, it is within 'respectful relationships' that important aspects of policy are enacted (Ahmed and Kitson 1993, Savage 1998) as well as addressing issues important to older people receiving care, such as accessing appropriate social networks, the negotiation of privacy, managing anxieties and concerns, enabling the maintenance of independence, autonomy in decision-making and managing changing care needs.

2.3.2 Sexism: Caring as 'women's work'

Three issues are important here: the assumptions about the role of family support made in policy and its implementation, the status of care work and the gender differences of those receiving care. The majority of older people and their carers are female (Travers 1996), where 'caring' is defined as an activity that occupies

20 or more hours per week (to distinguish it from the provision of purely practical help). Caring for older people is seen as 'women's work' (Oakley 1993) and the reliance in policy upon older women to look after older women both reflect attitudes towards women and assumptions about their roles in society and the family (Finch 1989; Finch and Mason 1993, Stacey 2005).

Family is the first port of call for those in need of support or care. Gendered assumptions about the caring role (Finch and Mason 1993) are reflected in policy. Although older people may have female relatives, they may not always be able to rely on their support as informal carers since female relatives may not necessarily fulfil the role of informal carer as assumed by formal staff developing discharge support packages. Furthermore, an individual may not feel that a female relative is the person best able to meet their needs. To ensure autonomous decision-making in the production of support packages, older people must be provided with a viable alternative to relying on family.

A second issue is the way 'caring work' is viewed (Stacey 2005). Older people are often cared for by semi-professional carers however, neither experience nor training is necessary to start work as a carer of older people. Levels of training and experience of care assistants vary and they may not necessarily have the skills necessary to provide support of an appropriate standard. I would argue this reflects an underlying view of the care of older people as non-skilled and common-sense work. However, this is not the case. Providing empathetic and appropriate support for older people is in fact highly skilled work, requiring some understanding of the need for a respectful and autonomous relationship, some understanding of

counselling and an awareness of ageism, its implications and how it can be tackled and avoided. This training and support is rarely provided or available to those who care for and support older people.

At a third level, gender is important in the experiences of those who are receiving care. An older man may carry with him cultural understandings from his youth, and the same is true for older women. Here I am referring to the gender division of work that may lead to differences in experiences of being older and ageing, as well as the differential impact this may have in terms of looking after oneself (Finch and Mason 1993). A particular cultural understanding of gendered roles may result in older men lacking the skills or motivation to complete household tasks traditionally considered the preserve of women and therefore leads to differing support needs.

2.3.3 Cultural conflicts

The issue of professionalism and the impact it has on the experiences of older people returning to care in their own homes after admission to acute care contains aspects relevant to the argument here on two main levels. Firstly, conflicts between professional power bases can lead to or maintain fissures between health and social care or medical and 'others'. Concerns with these fractures can be seen within both academic research and policy that aims to break through the 'Berlin wall' (Frank Dobson 1998 cited in DH 1998a: 1) that separates the two. To this end the Health and Social Care Commission was established following the introduction of the *Health and Social Care (Community Health and Standards) Act 2003* to coordinate and regulate practice and the standard of facilities, as well as the care and support available (CHAI & CSCI 2003). Primary Care Trusts

(PCTs) were established to implement this collaborative policy by incorporating within one institution and team, professionals and workers from all disciplines. The Single Assessment Process (DH 2001a, 2002a, 2004b) also represents an attempt to make the patient central and encourage collaboration and information sharing between professional groups in the case of an individual's care on discharge.

However, despite this aim to provide a seamless service, the domination of the medical expert within multidisciplinary teams (Powers 2003) raises the question of how collaborative is the team (Latimer 1998, Twigg 2002). This also reflects biases that exist at a deeper level; namely the domination of the management of health and illness by biomedicine and through biomedical solutions. This hegemony portrays biomedicine as the only valid view and the only acceptable approach to managing ageing and the changing needs of a person throughout the life course.

Relationships between professional health and social care workers and pharmaceutical industries must also be examined. Drug companies have been accused of inappropriate marketing (Moynihan and Smith 2002), in pressure selling to GPs, as well as the giving of 'freebies', from expensive conferences and meals out to mouse mats, pens and sticky pads with the name of a certain company or product. The relationship between these companies and nurse training is also of interest. Dressing companies providing nurse training days and the use of advertising literature from a specialist bed company to inform ward practice are issues that need addressing as they represent a relationship that is neither neutral

nor unbiased. Without tackling this biomedical cultural domination it will not be possible to provide older people with the seamless service that exists as a policy aim.

Relationships between professional workers themselves, as well as semi-professional formal health and social care workers can work against the aim of joined up practice. Conflicts may exist between different formal support services, due to different professional cultures or as a result of resource constraints, and can result in poor communication that hampers collaborative working (Dalley 2000, Atwal 2002).

Differing cultural understandings and the arising cultural misunderstandings between informal and formal care sources can shape relations of care. Informal support sources include family, friends, neighbours and other members of an individual's social network. Formal support can be either professional workers (for example, doctors, nurses, social workers, physiotherapists, occupational therapists and other specialist services, such as diabetic, incontinence or pain control) or semi-professional workers (for example, care workers, home support, wardens, meals-on-wheels). These two broad groups, formal and informal carers, may have different understandings of the problems faced by older people, their needs and the most appropriate way of meeting these needs. This difference in 'world view' can lead to misunderstandings and, at an extreme, conflicts between the two sources of care which may lead to a fragmented and inconsistent experience for older people.

As a user group older people returning home from hospital may experience disjunctures and miscommunications between agencies organising and providing support and care. This can impact on an individual's experience of hospital discharge as they may receive unclear or conflicting information and advice which may remain confusing as to how to manage changes in their care needs once home. Uncertainty about where to go for help may lead to no help being sought when it is needed, or necessary support not being accessible until a crisis occurs resulting in the need for consultation with health and social care professionals.

Cultural attitudes, such as ageism, can impact on the gap between policy rhetoric and the reality of receiving support. As a social group and a service user group older people are exposed to ageism in the wider culture, in terms of the options and help available to them. The support an individual receives reflects not only the availability of services, but also how this is 'enacted'. Therefore, central to a positive experience of receiving care is the success of 'respectful relationships' between those interrelated through care-giving. On an individual level, access to support and autonomy in planning and experiencing that support can be affected by ageist attitudes, conscious or unconscious, amongst those who provide the support.

Finally, many assumptions are made about the skill levels required for caring for older people that reflect both ageist and sexist attitudes, where unpaid caring work carried out by women is seen as 'common sense', 'unskilled' or as 'natural'. Ageist attitudes, still prevalent in wider society, may affect the care older people receive, especially as informal carers are largely unsupported in their day-to-day

duties and access to respite care for older relatives is not easily accessible, appropriate or cheap, leading to stress and fatigue. In addition, informal carers do not have access to ethical training, which would give them the opportunity to address ageist assumptions and attitudes in a reflective way.

2.4 Why listen: ‘Hearing’ older people’s experiences

The journey from hospital to home is influenced by many factors. Policy is seen as evidence-based. Yet this ‘evidence’ whose use and application is presented as neutral and objective has been shown to be patterned by political, economic and cultural factors that lead to an incongruence between the aims and the outcomes of policy.

Participation is a central tenet underlying health and social care policy in general and older people’s services in particular. Creative ways of accessing and understanding older people’s experiences of care have been presented (McCormack 2001), and applied to leaving hospital (Roberts 2006). Seeking a full understanding of how policy is ‘lived out’ provides an opportunity to evaluate the implementation and structure of policy; to assess the appropriateness of individual care arrangements and take as a starting point, older people’s views and experiences in the investigation of the impact of the implementation of policy in the ‘moment of care’. Therefore I explore the experiences of older people using a methodology aimed to produce inductive findings, which work from the bottom up and do not impose pre-assumed categories. A grounded theory approach was taken in the design of this project. The following chapter discusses methodology, explains the analysis process and includes an introduction to the older people who took part in this study.

CHAPTER THREE

EXPLORING OLDER PEOPLE'S EXPERIENCES: THE METHODOLOGY

This chapter presents the methodological approach underpinning this study. The design, data collection and data analysis are discussed and finally an introduction to the study participants is made.

3.1 Design: Choice of Methodology and Methods

After some revisions, a qualitative, grounded theory approach was used. In addition to a period of observation and the use of reflexive research diaries, a series of three unstructured interviews with each participant was proposed, to cover the entire discharge process. This data was to be used with other available and relevant data, to produce, through a process of constant comparison, an understanding of the discharge process as experienced by older people.

3.1.1 Choice of Methodology

The initial focus of this study was to explore the experiences of older people leaving hospital for home in the light of the newly introduced SAP (DH 2001a). A qualitative methodology was chosen as it provided an approach that allowed for the collection of rich, valid data that enabled older people to express experiences of going home in their own words (Polit and Hungler 1999, Silverman 2001, Bowling 2002). To access this data, semi-structured interviews were proposed, in a series of three, across the discharge process. However following a period of negotiating access to the DME, a change in focus

and refinement of the methodological approach was necessary. This resulted in a move from a more general qualitative approach, what Glaser calls 'QDA' (Glaser 1992, 1998), to a Grounded Theory approach. Grounded theory has been used in combination with quantitative methods within the positivistic paradigm, however to ensure the emic dimension, here it was combined with qualitative methods (Cutcliffe 2005).

3.1.1.1 Qualitative Methodology

The relative merits of qualitative and quantitative research methods represent a well rehearsed debate (Bowling 2002, Silverman 2001). The NHS as a large institution traditionally makes use of quantitative methods (Sim and Wright 2000, Bowling 2002) such as surveys, randomised controlled trials and large scale research projects that produce findings in terms of figures and statistics (Polit and Hungler 1999). However, over the last decade, certainly since the development of *The NHS Plan* (DH 2000a), there has been a growing inclusion of qualitative methods.

This methodological shift reflects and parallels a rise in policy emphasis on user empowerment and patient-centred care as health policies are based on a participative and consultative model that allows for negotiated decision-making, both on an individual and service user level. There has been a consequent rise in the use of qualitative research methodology (Nolan 2000), such as consultation with individual service users and representatives from user groups, including Age Concern and Help the Aged (*Our Care, Our Health, Our Say* DH 2006b). As part of this move, research into the care and support available to older people increasingly uses methodologies which place consultation, collaboration and the participation of older individuals and user groups as central to the process of policy and research generation and service commissioning.

Qualitative methods are effective in the exploration of the experiences of older people who receive support and who are considered ‘consumers’ of health and social care. There are four main reasons why a qualitative approach was adopted in the design of this project. First, qualitative methods allow the individual to be heard and to have a voice (Sim and Wright 2000, Mason 2002). Although quantitative methods, such as a survey or questionnaire, may be able to produce data and findings that include large samples, the structure of the questionnaire may reflect the interests and biases of the researcher rather than express the concerns of older people receiving support (Dalley 2000). Qualitative research methodology not only allows the older people taking part in the project the opportunity to talk about their experiences of receiving support in ways that may be highlighted in background research or pin pointed in health policy, it also provides the opportunity to raise issues that the researcher may not have considered or dismissed as unimportant. This may not have been possible if a quantitative methodology had been used. Also, as a project aim was to explore the experiences of older people, it was important to allow them to ‘speak for themselves’ (Dalley 2000, Nolan 2000).

Secondly, a strength of qualitative research methods is that allowing individual older people to talk in their own way about their lives leads to a fuller understanding of an individual’s point of view (Silverman 2001, Bowling 2002). This allows an understanding at an empathetic, as well as the practical level, of what decisions were made and what were the personally derived solutions to negotiating the discharge process.

Thirdly, there is the question of ‘truthful response’ (Marsh 1988, Sim and Wright 2000). Using a questionnaire or survey would not provide the richness of data that could be collected through a series of face-to-face interviews. Completing a survey requires

'fitting' the older person's experience into pre-defined categories; this is influenced by the priorities predicted by the researcher and only allows an approximate understanding of those older people taking part. An interview is a conversation, giving an opportunity to build rapport and trust, where experiences can be more openly expressed (Silverman 2001). It is not clear whether the answers on completed surveys represent the genuine situation of an individual. A questionnaire or survey may not reflect the varied responses to living through the discharge process, which come from the day-to-day experience of older people. Furthermore, aspects of investigation in this research project, such as details about an individual's management of private issues, represent sensitive information areas that respondents may not be willing to record on paper to an unseen audience.

Finally, each older person has different needs and differing access to support provision. Using qualitative interviewing methods allows the exploration of these individual differences in two main ways. First, it does not stereotype older people into groups such as 'dependent', 'mobile/immobile', 'able to cope with their own personal care' and 'needing help'. Secondly, it reflects the policy aim to produce support tailored to an individual's care needs, with their wishes and informed decision-making being at the heart of support planning.

3.1.1.2 Grounded Theory

Following meetings with the Head of the DME and the Lead for Implementation for the SAP in the local area, in combination with reading of the policy (DH 2002a, DH 2002b), two issues became apparent. First, that the SAP was not to be fully implemented until April 2004, outside the period available for fieldwork and indeed access. Second, and arising from the interview with the Lead for Implementation of the SAP, very few changes were planned, as current practice was seen as 'best practice', and a number of

central proposals within the SAP were already considered ‘in place’ and implemented through ‘best practice’. The strategy proposed for the implementation of the SAP was a matter of fitting current practice to the aims of the SAP, reconstituting and representing current policy to meet the requirements for the implementation of the SAP.

Some revision of the proposed research was required. It became even more important to look at the experiences of older people in the light of the fact that current practice was to continue. The aims then became to identify and describe the central social process in the experiences of older people leaving hospital for home; and in this way to develop a substantive, mid-range model that could express and/or explain older people’s experiences of this phenomena (Chiovitti and Piran 2003: 433). This level of theory was the most appropriate as, where Grand theory evolves as a result of studying a ‘phenomena’ in a number of different contexts, a substantive theory emerges from the study of a phenomena in one ‘situational context’ (Strauss and Corbin 1990: 174). Furthermore, identifying the level of theory is important as it supports the assessment of ‘fit’ in the evaluation of issues of rigour (Chiovitti and Piran 2003: 433).

This shift led to a more general research question: What are the experiences of older people leaving hospital and going home? What is the experience of receiving ‘best practice’? This change in focus necessitated a move from a general qualitative approach to a grounded theory approach as grounded theory has a number of advantages over other qualitative methods, such as phenomenology. Grounded theory provides a single, unified and systematic method of data collection and analysis (Glaser and Strauss 1967, Strauss and Corbin 1994, Strauss and Corbin 1998, Charmaz 2000). Where other qualitative methods may rely on the application of the general values of rigour, the lack of systematic

approach can make application of these principles and interpretation of the results difficult.

Grounded theory also allows a method for validating findings and establishing rigour through its simultaneous process of data collection and analysis, through the constant comparative approach in data analysis, through the concept of 'saturation' of categories, and through a refined version of the wider qualitative principle of trustworthiness, which includes the concepts of 'fit', 'grab', 'work' and 'modifiability' (Glaser 1978, Strauss and Corbin 1998, Glaser 2002).

In addition, grounded theory integrates well with quantitative methods (Glaser and Strauss 1967). This is particularly relevant in a forum where a positivist approach is highly valued and at a time when quantitative methodologists are increasingly triangulating their approach to include a qualitative strand that provides valid, in-depth data (Strauss and Corbin 1994).

To develop an understanding of the personal experiences explored through interviews, a 'grounded' analytic approach was taken. Grounded theory allows the exploration of experiences and the uncovering of categories that genuinely exist in the real world of those who are 'living the experience' (Glaser and Strauss 1967). Interpretive phenomenology also aims to understand meaning as it emerges from interaction and see these meanings as varying across social and cultural contexts and groups (Bowling 2002: 129). However where a phenomenological approach looks at meanings arising from interactions, within their specific contexts, grounded theory enables the systematic development of an emic and grounded understanding of the central social process

experienced by older people in their journeys from hospital to home that can be adapted to explore wider issues such as how older people manage change throughout their daily (healthy) lives.

3.1.2 Choice of Methods

Three main qualitative methods were used. An initial orientation period of observation was undertaken and a reflexive research diary was maintained throughout the research process. Once access was established, unstructured interviews were carried out over three stages of the discharge process: in preparation for home, in the first week after returning home and after eight weeks of being back at home.

3.1.2.1 Observation

A period of observation was necessary in the initial stages of the project. The process of research very often starts with a literature review of the central issues addressed by people working in the subject field. However, grounded theory methodology demands that concepts used to build theory are grounded in and emergent from the empirical data. Therefore, both research and policy literature were only consulted as a result of issues, concepts and ideas that arose during data collection and data analysis. Literature searches were not conducted until analysis had progressed to 'category building' (see Section 5.1 Links within Categories: developing dimensions).

Observation proved useful to chart the ward routine and the methods of preparation of individuals for discharge and also to gain access to participants. A month's observation within the Department of the Medical Elderly at an inner city northern NHS Trust hospital was undertaken to understand the ways hospital staff assessed individuals and designed discharge packages. The aim of this was to build on my previous experience as a registered nurse and develop a contemporary understanding of the practicalities of

hospital discharge, hence to understand the process by which the older person is prepared for discharge and how the discharge process is implemented.

The observations carried out focussed on two processes. First, bedside observations aimed to capture the nature, content and timing of patient interactions, both verbal and non-verbal, in the bedside area (Latimer 1993) in order to better understand how being in hospital 'was' for older people. Secondly, 'moments of assessment' were observed (Latimer 1993, Twigg 2002), including observations of professional assessments namely: ward rounds (medical discharge), physiotherapist assessments, occupational therapy assessments, social work assessments, case conference and nursing assessment (discharge). Times of medical ward rounds, those professionals who attended and the process of medical discharge were observed. Field notes were made in the research diary as soon as possible after these observations. Notes were not made during these periods of observation in an attempt to reduce the impact of the researcher presence (Silverman 2001, Bowling 2002) and to minimise potential distraction to professionals, the patient and the researcher.

The process of preparation and assessment for discharge made by both the physiotherapist and the occupational therapist were observed and again noted as soon as possible after the period of observation. This included assessments on the ward and home visits as well as the process of daily therapy. The process by which the social worker assessed individual needs and provided an interface between hospital and community social services support was documented. A 'case conference' was observed, that is, the moment when an individual and those involved in their care meet as a team and discuss the needs of the individual and the possible support that will be required.

The field notes, recorded in the reflexive research diary, provided further data about the context and process of hospital discharge for older people and were used as part of data collection and data analysis to build experience codes, categories and their dimensions.

Another advantage of observation in this context is ‘immediacy’ (Silverman 2001).

Observation provides the researcher with a firsthand experience of how discharge is achieved and does not rely entirely on accounts given by those carrying out the process of assessment, planning and implementation. This is necessary as there is a difference between what people say they do and what they do in reality (Deutscher 1970). This period of observation provided the opportunity to explore the reality of how the ward staff operate the process of discharge and how experiences older people have of preparing for home are mediated by the practicalities of individual needs and the restrictions of the ward environment.

A period of observation also allowed access to the opinions of those professionally trained and working within the Department for The Medical Elderly (DME). Ideas not considered by the researcher that arose from the reality of professional assessment of those returning home could be considered, so providing a fuller picture of the process. Furthermore, the month of observation allowed the researcher to gain access to appropriate participants in an ethical manner.

However using this method to understand the way discharge is achieved has certain limitations. A month is a short period in which to understand this complex process and only allows a superficial understanding of the procedure by which discharge is achieved. A more in-depth understanding of the negotiations and assumptions underlying

professional assessment and the construction of discharge packages would require hospital-based research beyond the scope of this project (see Latimer 1993). Neither was it possible in a month to chart the complex interactions present within the multidisciplinary team, nor between older people and professionals in any rigorous manner, but merely to provide a background understanding of the place of older people and relevant (as defined by those under study) carers within the process.

The Hawthorne affect may be apparent and the presence of an 'observing researcher' may have an impact on findings (Silverman 2001). This effect can be minimised by the researcher spending enough time on the wards so as to become accepted by staff, by 'blending' into the background, not wearing a uniform or loud or obvious clothing and not becoming associated too strongly with any group involved (Polit and Hungler 1999, Silverman 2001, Bowling 2002). However, a major disadvantage in relation to the subsequent change of methodology towards grounded theory was that this period of observation made understanding the experiences older people had from *their* point of view more difficult.

3.1.2.2 Unstructured Interviews

A series of three unstructured interviews was carried out with each participant: the first before discharge and during the period of assessment and planning, the second immediately after discharge within the first week of returning home and the third after eight weeks post-discharge. Each interview lasted between 30 minutes and two hours, the exact length being determined by the time available and the wishes of the participant. Less than 30 minutes did not allow enough time to cover all the areas in the topic schedule and for the participant to raise themes that they felt important but more than two hours led to tiredness and difficulty in concentration for both interviewer and interviewee.

A series of three interviews over an eight week period was undertaken for three main reasons. First, this approach allowed an opportunity to develop a relationship with those taking part that potentially led to a more accurate and rich understanding of older people's experiences. Secondly, it provided an opportunity to explore changing experiences across the discharge process and thirdly, this approach provided a point at which the success of discharge planning in providing support that an individual felt appropriate could be assessed.

A topic guide was produced for each interview in the series to give some focus to the information collected (Bowling 2002, Polit and Hungler 1999, Silverman 2001, Strauss and Corbin 1998) (see Appendix 1). It was hoped that, through exploration of certain subject areas, particular issues would arise that represented the problems seen as pertinent by the participants and not follow too closely an agenda set out by the interviewer. The use of an interview schedule provides a useful opportunity to explore emerging codes and categories, as ideas arising from the concurrent analysis structure the questions asked. Secondly, it allows a temporal comparison between interviews. Attitudes of a respondent towards a particular topic may change during the series of interviews, for example, the experience of returning home and managing may change an individual's attitude to the process of assessment and discharge (Lloyd 2006). Thirdly it allows a certain comparison between respondents with reference to emerging topics (Silverman 2001). Fourthly, as well as enabling the process of refining and developing categories, using an interview schedule allows the researcher to clarify and test understandings of the relationships between them.

Interviews were audio-taped, with the permission of the respondents (see Appendix 2 for the consent form used), to ensure accurate transcription and analysis of data collected (Silverman 2001). Although audio-taping and analysing interview transcripts is not always recommended with grounded theory (Glaser 2004) it can enhance reliability (Polit and Hungler 1999, Silverman 2001) as the words and phrases used by the respondent can be analysed fully at a later date. Responses can be reviewed as required, facilitating the use of the constant comparative method (Strauss and Corbin 1990, Glaser 2001) by allowing a retrospective use of theoretical data sampling (Wuest 2006) and reducing problems such as misinterpretation at the time of the interview and errors due to poor note-taking or memory lapses on the part of the researcher. It also enables interviewers to provide interviewees with their full attention, reducing the distraction caused by note-taking to both parties (Bowling 2002).

Notes were made as soon as possible after the interview and this allowed for information and observations to be recorded, for example non-verbal communications that were not picked up by the audiotape (Silverman 2001). Note-taking during an interview may distance the researcher from participants, highlighting the research process and emphasising rather than playing down the role of the researcher (Polit and Hungler 1999, Silverman 2001, Bowling 2002). Audio-taping and diary keeping allowed the interaction between researcher and participant to flow as a normal conversation (Bowling 2002) putting the participants at their ease and allowing themes to emerge about their experiences.

By not providing pre-coded response options, as is the case with questionnaires, but leaving participants free to respond in their own way, it is possible to obtain a fuller, more

inductive understanding (Bowling 2002). The participant is not restricted to the pre-defined themes of the interviewer. Unstructured interviewing, therefore, allows participants to raise issues that the interviewer may not have considered, thus increasing the credibility of the research (Silverman 2001). Furthermore, the convergence of topics both within and between interviews shows that a certain saturation of information had taken place (Strauss and Corbin 1998), and that some common issues or concerns were being noted. This also increases the 'trustworthiness' of the research (Strauss and Corbin 1998, Cutcliffe 2005).

Such interviewing also allows for probing and more detailed questions to be asked (Glaser 1998, Bowling 2002). This enables the researcher to delve more deeply in certain areas and allows respondents to express their meanings more fully than is possible with other methods such as questionnaires. Furthermore, interviewing does not assume literacy (Bowling 2002). This is relevant for the age group under study, as not all have had access to education. In addition problems arising from issues such as poor eyesight and poor handwriting can be avoided. By talking about the experience of hospital discharge older people are able to describe their experiences in their own words (McCormack 2001). This may reveal issues not expressed overtly which may be uncovered using the constant comparative method (Strauss and Corbin 1998, Glaser 1998)

There are disadvantages with using this approach however. Interviewer bias can be seen as the main problem (Polit and Hungler 1999). This may be included in research findings when the social background of the interviewer affects the response made in an interview (Bowling 2002). This may be as a result of a mistrust or lack of rapport between interviewer and interviewee but also can be due to an 'over identification' where the

interviewer relates to the participant as if certain responses can be taken for granted, thus distorting outcomes (Silverman 2001). A reflective and a non-judgmental approach both work to reduce this effect. In addition, grounded theory provides the tool of ‘theoretical sensitivity’ (Glaser 1978) which works to ensure that it is pertinent theoretical threads that are followed not merely the interests, or the views, of the researcher (Glaser 2002).

3.1.2.3 The Interview Series

A series of three interviews were planned with each participant with the view to identifying any changes in the experiences of older people in relation to the discharge process: one while in hospital, the second within the first week home and the third eight weeks after the return home. These interviews were labelled A, B and C respectively and the data reported in Chapters Four and Five will be identified using these letters.

Interview A: Preparing for Home

The first interview, in the series of three, took place within the hospital setting at the participants’ bedside or day room where appropriate. This interview aimed to explore the feelings and experiences of older people whilst in hospital and during their preparation for home, with a specific focus on their participation in the process and their anticipation of the return home. These initial interviews had a loose focus, that is ‘What is getting ready for going home like for you?’ General, open topics were discussed in a conversational exchange.

Interview B: Getting Home

The second interview was carried out at the home of the participant within the first seven days of discharge from hospital to home. This interview was carried out for two main reasons: first, to explore the experiences of the older person in their initial return home as this represented a change in the context of their experiences. The first few days home may highlight problems not previously anticipated by the older person due to a change in their

health condition, a change in home circumstances and changing needs. Secondly, to provide the opportunity to explore codes and categories emerging from the first set of interviews (see Section 3.2.1.2 Theoretical Sampling). Questions were guided by tentative codes, using ideas arising from open coding of the first set of interviews.

The issue of consent was again discussed at the beginning of this second interview to ensure that the participant remembered the project, continued to give their consent to take part (Grout 2004), understood they were free to withdraw from the project and were clear that the researcher was not a member of the health and social care team that may be supporting the older person at home (Locher *et al.* 2006). There was no drop out at this stage, and all those who had participated this far finished the series of interviews. The issue of participant drop-out will be discussed in Section 3.2.2.2 Recruiting Participants.

Interview C: Being Home

The third interview in the series was carried out two months after hospital discharge. Continuing care packages, including for some the provision of a home carer, generally last for six weeks after hospital discharge as they are designed to provide supported rehabilitation after leaving hospital. The aim of this interview, therefore, was first, to explore the experiences of living at home after immediate post-discharge support had ceased; secondly, to provide a point from which to assess the appropriateness of support as seen by older people; thirdly to explore older people's experiences of change both from previous arrangements and from hospital support and finally to investigate the part they played in decision-making once home. On a methodological level, this interview allowed the opportunity to further explore and define categories with the aim of reaching 'saturation' (Glaser and Strauss 1967), that is, when "no further insights emerge that are relevant to the theory when additional data is analysed" (Kennedy and Lingard 2006:

104). Questions were guided by emerging categories, their dimensions and properties, and the relationship within these categories, in terms of links between sub-categories, and finally, the relationship of these categories with the core category.

Interviews were carried out and audio taped with the continued consent of participants. It was made clear that they could withdraw from the project (Grout 2004) and this was neither connected to nor would affect the work carried out by health and social care professionals (Locher *et al.* 2006). The issue of confidentiality and the proposed uses of the information provided by the participant were discussed and participants were ensured that confidentiality would be strictly observed (BSA 2002, Butler 2002)

3.1.2.4 Research Diary

Keeping a research diary is essential in the grounded theory approach (Hutchinson 1986) and was used in three main ways: it provided a means of thinking reflexively; it allowed me to keep memos throughout the concurrent data collection and analysis process central to the constant comparative method (Glaser and Strauss 1967, Glaser 1978, Strauss and Corbin 1990, Charmaz 2000), and allowed for organised timetabling of the interviews.

Reflexivity: Me as....

A reflexive research diary was maintained throughout the research process, including the initial stages of research, the fieldwork period and the period of analysis and writing up. Reflexivity allows a contemplative look at the experiences of undertaking research and can be used to allow analysis to take place concurrently with the fieldwork process (Mason 2002, Doucet and Mauthner 2002).

It is important to make clear the biases and underlying assumptions that may influence my approach, project design or analysis (Darlington and Scott 2002). Using a reflexive

research diary provided me with the opportunity to explore my underlying assumptions and preconceived value judgements. Within a qualitative school, a reflexive approach is part of the methodology as an underlying aim of research design is to expose the biases held by the researcher (Shakespeare 1993). To understand and interpret the findings that the researcher generates it is necessary to appreciate the researcher's background and view point (Darlington and Scott 2002). Chiovitti and Piran (2003: 431-2) refer to the importance of using the research diary as a tool to limit the potential imposition of a researcher's viewpoint, without analysis, on the process of research and therefore in part reflexive use of a research diary can support 'trustworthiness' (*ibid*).

As a registered nurse there are certain methodological issues that I needed to address with regards to my role whilst carrying out research. My status as a registered nurse made the strategy of approaching nursing staff to act as 'gatekeepers' an effective one. My previous experience working as a staff nurse within the unit helped to make me accepted into the ward team; it also allowed me to pick times of day that did not interfere with the ward routine. My knowledge of the multi-disciplinary hospital team meant I was able to ask the appropriate health care professional about specific issues where necessary. Finally, as I have previously worked with older people in a ward environment and in similar situations, I have developed a number of communication skills that made approaching older people to ask them to participate easier.

My nursing education also raises ethical issues in terms of my professional role on the ward. Due to issues of patient confidentiality (DH and CC 1997, DH 1998b) unless I am an employee of the Health Trust I am not allowed to help with specific treatments, however other activities, such as helping an older woman back to her bed area may not be

seen as providing professional care. Where there are grey areas such as a serious threat to safety, I must observe the code of practice set out by the NMC for registered nurses (NMC 2002).

As stated by Silverman (2001), part of the problem of the Hawthorne effect is the issue of over identification with participants. This would influence research findings, represent an imposition of researcher assumptions and misunderstandings and not allow older people to express their opinions in an unbiased environment. Being aware of this as a problem limits the temptation:

I don't want patients to think I am part of the nursing staff, but telling them that I am a trained nurse may make them feel more confident in my ability to maintain confidentiality. I want them to feel that I am on 'their side' (Research Diary 2, 2002).

As a researcher it is necessary to act reflexively, identifying personal biases and assumptions that may impact on my understanding and interpretation of the data collected and my part in this process (Shakespeare 1993). This requires both a critical reflection of my skills as an interviewer (Schön 1991) and a critical analysis of the links evident between my theoretical understandings and issues that arise during data collection. This requires 'theoretical sensitivity', that is the ability to identify and follow theoretical threads emergent from the empirical data, and the research diary provides a place where this skill can be rehearsed and practised.

Using a research diary (Bell 1999, Silverman 2001) allowed me to record a theoretical interpretation of older people's experiences and to build themes into categories through a

synthesis between observations, the literature review and emerging ideas from interviewing (Glaser and Strauss 1967, Strauss and Corbin 1990, 1998). This was achieved through the use of ‘memos’.

Memos

Strauss and Corbin define memos as: “The researcher’s record of analysis, thoughts, interpretations, questions and directions for further data collection” (1998:110). These were dated and recorded in the research diary and saved as hyper-linked documents to quotes in the transcripts of interviews with participants (using Word). Any memo developed in the hard copy research diary was entered as a document hyper-linked to the appropriate quote in an interview transcript; any memo developed on the computer was printed out and pinned into the research diary at the appropriate chronological point. In this way arising ideas could be kept together and at the same time linked to the appropriate interview quote *in situ*. Memos were used throughout the process of constant comparison, becoming more conceptual as the research proceeded (Strauss and Corbin 1998: 153). The constant comparative method will be discussed more fully in Sections 3.2.4 The End of Data Collection and 3.3.1 The Constant Comparative Method.

According to Charmaz (2000: 517-518), memo writing “helps researchers a) to grapple with ideas about the data, b) to set an analytical course, c) to refine categories, d) to define the relationships among various categories and e) to gain a sense of confidence and competence in their ability to analyse data.” There are numerous types of memos, those mainly used in this research were: field notes, operational notes, code notes and theoretical notes.

Field notes are observations, details about interviews that were not captured on audiotape and initial ideas that occur during interviews and are recorded immediately afterwards. They contain data that can be used in the analysis. Operational codes are “memos containing procedural directions and reminders” (Strauss and Corbin 1998: 217) and allow for planning. These were important on a practical level during the process of data collection as they were used to record appointments made for interviews B and C and monitor timetabling.

Code notes are memos containing ideas about codes and how they link together during initial and subsequent analysis of data and in this respect they contain the ‘products’ of coding (Strauss and Corbin 1998: 217). These issues will be discussed in more detail in Section 3.3.

Theoretical notes range from short notes about how theory links with emerging codes and ultimately categories, to longer notes that explore theoretical implications. Strauss and Corbin refer to these as “sensitizing and summarising memos that contain an analyst’s thoughts and ideas about theoretical, sampling and other issues” (1998: 217).

Memos therefore represent a central tool in driving data collection (through theoretical sampling), supporting analysis by providing the opportunity to think conceptually about the information available and theorising about the ways these data are related; and finally making links between emerging categories, their sub-categories and related issues discussed in the theoretical literature.

These ‘memo types’ however, are not distinct and one memo may contain one or all dimensions described above (Strauss and Corbin 1998: 218). Other methods suggested for looking at the relationships within the collected data include the use of diagrams (Strauss and Corbin 1998). These can be seen as “visual devices that depict the relationships among concepts” (Strauss and Corbin 1998: 110). Diagrams were used during axial coding, to identify and explore possible links between categories and their sub-categories; and during theoretical coding, to explore possible links between categories and the emergent core category. Diagrams were developed as the process of constant comparison progressed and recorded and refined in the research diary.

Planning and Practicalities

Finally, the research diary provided a place where the complex process of timing interviews could be recorded and managed. The series of interviews proposed meant that not all participants took part in Interview A at the same chronological moment, but rather in relation to their position in the process of hospital discharge. Therefore, careful planning was required to ensure that individuals were interviewed within the first week (Interview B) and during the eighth week (Interview C) of their return home.

3.2 Data Collection: Sampling, Access and Ethics

The collection and analysis of data were carried out simultaneously as a constant comparative approach was taken during this period (Glaser and Strauss 1967, Strauss and Corbin 1998). The analysis of initial interviews suggested a number of emerging categories, which in turn guided further interview schedules (Strauss and Corbin 1994). This provided a method for further exploring and refining emerging categories, or indeed discarding, those that became peripheral to the central phenomena under study. However, there are some distinct issues in relation to data collection that must be addressed;

namely: sampling, access and ethics. Data Analysis will be discussed in Section 3.3 below.

3.2.1 Sampling

3.2.1.1 Sampling Technique

Using an appropriate sampling method is essential if the research findings are to be 'trustworthy' (Sim and Wright 2000, Silverman 2001, Chiovitti and Piran 2003).

Sampling methods can be seen to be analytically linked with forms of methodology and analysis (Mason 2002). As the analysis of the generated data was based on an inductive exploration of emergent categories through coding as described in the constant comparison approach (Glaser and Strauss 1967, Marsh 1988, Ballinger and Payne 2002), issues of sampling concentrated not on statistical representativeness but followed a theoretical thread. The interest here was to discover 'how it was' for those being discharged home.

I therefore initially defined my study group as those with knowledge of the process and context of the phenomena under study (Strauss and Corbin 1998): that was older people, over 75 years of age, undergoing discharge from the DME in a northern hospital trust, to their own homes. Initially convenience sampling was used (Sim and Wright 2000, Silverman 2001, Mason 2002), that is: "the drawing of a sample in terms of the ready availability of sampling units" (Sim and Wright 2000:120). This method has been used to study complex issues in a health care setting (Bowling 2002:187) and is recommended for the initial stages of a grounded theory investigation (Glaser and Strauss 1967). Here, the sample was restricted within certain criteria, of age and experiences with reference to 'being discharged from hospital', 'going to their own homes', 'having self defined care needs', 'having professionally defined care needs' and 'consuming support provision'.

Potential participants were identified through care staff working with them in a ward setting, in line with Caldicott Guidelines (DH and CC 1997, DH 1998b) concerning confidentiality. The initial sampling method was therefore 'convenience sampling' although within certain research and professional criteria (Sim and Wright 2000: 120). There is a consideration of bias needed here. As nursing staff may propose and approach certain patients that they feel are 'appropriate', there is a danger therefore that the sample gathered may not be representative of all those older people leaving hospital for home, but just those the staff felt would be approachable and articulate.

A further consideration in the sampling technique is the use of data collected from within one Health Trust, one context. It can be argued that a fuller picture of experiences on the return home would be provided through inclusion of data from a number of Hospital Trusts and a number of regional areas. Although not essential in the development of a mid-range substantive theory, a 'cross context' approach may identify regional differences that exist, which would allow for the fuller development of categories and modification of any theory or model arising here (Glaser 1978).

3.2.1.2 Theoretical sampling

For subsequent interviews, theoretical sampling was used to guide data collection (Glaser and Strauss 1967, Chenitz and Swanson 1986, Strauss and Corbin 1990, 1998).

Theoretical sampling is a central concept in the constant comparative approach that underpins Grounded Theory. It refers to sampling on the basis of concepts that have proven theoretical relevance to the evolving construct (Strauss and Corbin 1990: 176).

This requires iterative data collection and data analysis techniques, where data is collected, coded and analysed simultaneously and ideas arising from this process provide a focus for further data collection (Chenitz and Swanson 1986: 9).

Theoretical sampling is representative of the systematic approach within grounded theory, and its use increases the trustworthiness of the research as it allows “us to identify conceptual boundaries and pinpoint the fit and relevance of our categories” (Charmaz 2000: 519).

Although this is used in the sampling of participants, in this study access was limited and a revised version of theoretical sampling was carried out in relation to the questions asked and the areas probed in subsequent interviews and in relation to search criteria of the academic and theoretical literature. In this way the development of categories was shaped by both identifying emerging dimensions and limiting them. A full range and variation of each category was sought to guide the emerging construct (Silverman 2001: 108).

3.2.1.3 Participant Qualities

Those approached to take part in this study were over 75 years old and consumers of acute hospital services. More specifically they were users who were planning, awaiting and experiencing discharge from acute hospital settings to their own homes. All participants were recruited from within the Department of the Medical Elderly (DME) of a local Hospital Trust, which is spread across two hospitals in the group.

Age

The age group 75 years and above was appropriate for two reasons. First, it represents a statistical category referred to both in the academic literature and within government policy (Dalley 2000). Secondly it represents a growing group with an increasing public profile. Recent population estimates predict a rise in numbers of those over 75. Currently, five percent of men and nine percent of women are over 75; in 2025 this is predicted to rise to nine and eleven percent respectively (ONS 2002). Increasing public concern with

the standards of care of the older person has led to the development of the *National Service Framework for Older People* (DH 2001a).

Gender

Initially the sampling method proposed was one that accounted for the gender balance within the population of interest, with an initial proposal to interview 30 participants, 10 men and 20 women (ONS 2002). Due to practical constraints, which will be discussed below, 12 participants took part in the project, two of whom were men and ten were women. However, as theoretical sampling was used, which follows the theoretical threads to identify appropriate participants, valid, although possibly gendered, interview data was collected.

Ability to consent

Participants must be able to provide informed consent (British Sociological Association 2002, DH 2001b, 2001c, Butler 2002). Those with serious mental illness or mental disability, therefore, were not seen as appropriate candidates. Nursing staff, in their role as ‘gatekeepers’, introduced only those considered medically competent of giving consent (Arber 1993, Hornsby-Smith 1993). Those with mild confusion were not excluded if they were considered capable of providing informed consent, as their point of view and experiences offer an important and relevant dimension (Golden and Sonneborn 1998, Bauld, Chesterman and Judge 2000) to this project. Those who were dying or in extremes of distress were not approached to take part in the research.

3.2.1.4 Sample size

Initially, a sample of 30 case studies was proposed with the aim of providing a ‘user view’ of the process of leaving hospital and returning home (Ungar 2001). However, this size of sample proved impractical given the time and access constraints of the research project.

Of those initially recruited to the study and completing the first interview (32), only 12 completed the full series of three interviews.

The size of a sample is traditionally linked in quantitative research methods with the validity and reliability of findings (Arber 2001). For research to measure what it sets out to measure and be replicable it must draw upon data from a sample that is statistically representative of the wider population (Marsh 1988, Arber 1993). In this sense, findings can then be seen to be ‘trustworthy’ and ‘generalisable’, and so applicable to the wider population and different groups. However, those within a ‘statistically representative sample’ are measured only on easily defined properties, such as age, gender, ethnicity and geographical residence; they may not be representative of the experiences of a population or group of interest. In inductive research that sets out to uncover, in this instance, themes that lie within the experiences of older people, it is not possible to pre-define the dimension from which to draw a ‘representative’ sample.

As qualitative methodology is concerned with uncovering, exploring and understanding social relationships and social processes (Bowling 2002); it is the “depth” (Silverman 2001) and “richness” (Bowling 2002) of the data that is of interest. Theoretical sampling is ideally used as this approach aims to recruit participants with experiences relevant to the social process under study. Small samples are therefore appropriate within qualitative social research (Arber 1993, Ungar 2001, Mason 2002, Bowling 2002). In Grounded Theory, a sample is of sufficient size when the same stories, themes and categories start to emerge, that is, when ‘saturation’ is reached (Glaser and Strauss 1967). Twelve participants taking part in a series of three interviews provided 36 transcripts to analyse in addition to field notes and memos, the combination of which provided a sufficient depth

and richness of information to allow an insight into older people's experiences of hospital discharge and returning home. Whether saturation was achieved is discussed at other points (see Chapter Six).

3.2.2 Access

In order to begin data collection and the associated analysis, access both to the context and to those with the knowledge and experience of the phenomena under study was necessary. These issues and problems arising from this process are discussed in this section.

3.2.2.1 Access to Context

University Ethics Committee

Ethical clearance is necessary to gain access to appropriate participants and to carry out research projects based in a university. When this study was developed it was seen as sufficient to gain ethical clearance from the NHS Local Research Ethics Committee. Since fieldwork was completed, University Ethics Committees have been established that control and monitor the ethical issues underlying research carried out through a university. If this project were to be repeated, ethical clearance from an UEC would be sought.

Local Research Ethics Committee

To gain access to NHS patients to act as participants for this project a number of interested parties were contacted, the Local Research Ethics Committee (LREC) and the Research and Development department within the local hospital trust, the Caldicott Guardian, nursing management and those managing and staffing the relevant wards.

A proposal and protocol for the study were submitted to the LREC, the project was approved under the condition that the committee were to be informed if the research plan

changed. This was necessary on one occasion and a revised proposal was submitted and approval given as outlined below.

Initially the project focussed on the implementation of the *Single Assessment Process* (SAP) (DH 2002a) in accordance with the *National Service Framework for the Older People* (DH 2001a). It is a matter for the local health trust how parts of the SAP are to be put into practice and therefore implementation can be seen as locally contingent (Acheson 1998, Wanless 2006). Following consultation with the nursing manager with responsibility for the implementation of the SAP within the Health Trust, it was made clear that the full implementation would not be achieved until April 2004 and that certain principles only would be in place during the timescale of this project. These principles were those that were already considered 'best practice' in the provision of effective and appropriate discharge packages, such as the emphasis on 'user-led' needs assessment and the centrality of user involvement (DH 2000a, 2002a). To investigate the implementation of the SAP was therefore beyond the scope of this project and the focus of the study shifted. The experience of inclusive decision-making during the preparation for returning home and the impact this had on the experience of the return home became central.

Caldicott Guardian

The protocol and project proposal were forwarded to the Caldicott Guardian, together with an information leaflet (Appendix 3) and the proposed consent forms (Appendix 2 and Appendix 4) to be used in the study. The Caldicott Guardian protects the confidentiality and identity of people seeking care within a health trust and it was therefore essential to get project approval from this official. The issue of the initial introduction of the researcher to the potential participants was raised. Receiving hospital care is a matter of confidentiality and therefore nursing staff must ask for the consent of

the patient before informing the researcher of the patient's presence on the ward. To fulfil this requirement, nursing staff acted as 'gatekeepers', making the first approach to those they felt appropriate, providing potential participants with an outline of the project and asking for consent to introduce them to the researcher. All participants were accessed this way.

Nurses, Doctors and Other Associated Professionals

Initially a summary of the project proposal and a covering letter asking for permission to research on the wards had been sent to all charge nurses in the Department of the Medical Elderly (DME). However the response rate was poor. During meetings with the Research and Development department it was suggested that the Director of Nursing be contacted and that introductions to nursing managers and charge nurses in the relevant areas could be made. Permission was gained from the Nurse Manager of the DME and a meeting with charge nurses was organised. Following a presentation of the proposed project and a chance for questions and answers, the senior nursing staff gave their consent for fieldwork to be carried out on the wards for which they were responsible. Issues arising from my status as a nurse are discussed above in 'Reflexivity: Me As...' (See Section 3.1.2.4).

The medical team working within the DME and providing care for the participants were informed of the research project and approval by consultants was given. The physiotherapists, occupational therapists and social workers working within the DME were also approached to gather information about how older people are assessed and prepared for hospital discharge.

Researcher

As a researcher working with vulnerable adults I was required to undergo a police check and as a registered nurse I had to fulfil professional requirements and adhere to the *Nursing and Midwifery Council's Code of Ethical Conduct* (NMC 2002).

3.2.2.2 Recruiting Participants

The recruitment of participants to this project required three separate but related phases: an explanation and discussion of the proposed research with nursing and other relevant professionals, the introduction of the researcher to potential participants through nursing staff and an explanation and discussion of research with potential participants.

Access to older people in their own homes was central to the design of this project; therefore permission for this from the participants was necessary during recruitment to ensure the full series of interviews could be completed. During the initial meeting and in the leaflet (see Appendix 3), it was explained that it would be necessary to make two visits to interview participants in their own homes, first, during the initial week home and secondly after they had been back in their own homes for eight weeks. Any questions about this were answered. Family, friends and neighbours were also consulted where it was considered appropriate by participants.

In most cases, the date of hospital discharge was known and I was informed of this by the nursing staff or the participant and made a note of this in the research diary following interview A. However, there were occasions when nursing staff or participants were not aware of the exact date and on these occasions my presence on the ward alerted me to any participants who were being discharged. On the three occasions this happened, following

a ward round during which the participant had been medically discharged and the care team felt appropriate discharge arrangements were in place.

During the first week post-discharge, I phoned as agreed, confirmed the address and organised an interview at a time convenient to participants. The interview times, addresses and telephone numbers were logged in the research diary. This way the timing of interviews and the interviews yet to complete could be monitored and managed.

3.2.2.3 Problems

Older people were free to decline participation in the interview series at any point as consent was considered both negotiated and on-going (Butler 2002) (see Section 3.2.3.3 Consent). This was made clear at the beginning of all interviews and at the end of interviews A and B. Many participants, although happy to talk about their experiences on the ward, were reluctant to be interviewed in their own homes. As a result, although over 30 individuals were initially recruited and completed Interview A, many were reluctant to continue with their participation once they returned home. Therefore, of the initial 32 who completed interview A, only 12 completed the full series.

Four completed the interview A but when asked for contact details, did not wish to take any further part. Eight declined to continue their participation when contacted by phone to arrange the second interview and two phoned me to let me know they no longer wished to take part. I was unable to contact three participants after discharge, either having the wrong number or receiving no answer after a number of tries. In addition two older women moved away from the area, and one died before discharge. Twenty participants who initially consented to take part therefore did not finish the full series of interviews.

For those who declined to continue with the project, four main reasons were given:

- Too tired. One said ‘I really can’t be bothered love’
- Too Ill (readmitted)
- Losing touch
- Wanting to forget hospital and formal contact

The reason for this initially strong rate of participation followed by a high drop-out rate is unclear, but not uncommon (Locher *et al.* 2006). It may be that initially taking part in research is seen by the individual as of some advantage to their immediate care (Locher *et al.* 2006). It may be that older people are in hospital and bored, and therefore are happy to help. However, being interviewed at home is inconvenient and a commitment they did not feel would advantage them or they felt too tired and ill. Furthermore, older people may be making a security assessment of the risks of inviting strangers into their home and having their names linked with sensitive information including their address and telephone number.

3.2.3 Ethics

When working with what is considered a ‘vulnerable group’, fulfilling ethical considerations is essential in order to gain access; to meet the research guidelines of the commissioning and relevant professional bodies; to stay within the law and to ensure rigour. Gaining ethical clearance, maintaining and addressing issues of confidentiality and consent, considerations in relation to home interviewing, ensuring a non-judgmental approach and producing non-exploitative research are discussed below.

3.2.3.1 Ethical Clearance

Ethical clearance was necessary not only to gain access to participants, but also to ensure that lawful requirements were met (*Data Protection Act 1998, Human Rights Act 1998*) and will be discussed in more detail below. To meet the conditions required by the NHS

Local Research and Ethics Committee certain ethical considerations were necessary. An initial meeting with potential participants was necessary to give an opportunity for introductions and discussion about the research. Questions were answered and potential participants were given a leaflet explaining the purpose of the research (See Appendix 3). It was important to emphasise four issues: confidentiality, consent, a non-judgemental approach and non-exploitative research methods.

3.2.3.2 Confidentiality

Confidentiality was maintained on a number of levels. Participant information was not attributed to the individual by name, changed names were used throughout. Audiotapes and transcripts of interviews were coded so individuals would remain anonymous. The Caldicott Guardian (see Section 3.2.2.1 Access to Context) was informed and to ensure confidentiality nursing staff acted as 'gatekeepers'. As data were held on computer, the *Data Protection Act 1998* was observed. Information held was coded and audiotapes and interview transcriptions were kept at the university, where access was restricted to the researcher and research supervisors.

The notion of confidentiality was briefly explained to participants, stressing that information is shared following strict guidelines including the need to report unlawful and unethical practice. Reassurance was given that information gathered during the research process would not be passed to family, friends or staff, that full confidentiality was assured and that those participating would suffer no negative consequences as a result of the information gathered.

It was emphasised that the interviews were to be audio-taped. This was necessary to ensure the older person understood the way information would be recorded and why. Again issues of confidentiality were discussed.

3.2.3.3 Consent

Fully informed patient consent was essential (DH 2001b, 2001c, BSA 2002). To ensure this, an initial meeting provided an opportunity to explain the aims and design of the project for the researcher and to ask questions and clarify any points for the potential participant. This discussion was extended to relatives and carers as requested by the individual for two main reasons. First, this enabled a wider understanding of the participants' home care and secondly, allowed the older person the opportunity to discuss their potential participation with a person who they knew.

Consent is required from the participant to acknowledge their presence within the health and social care system (*Caldicott Guidelines* DH and CC 1998), to gain access to any written documentation such as assessment documents, to allow the observation of moments of assessment such as home visits with the occupational therapist, to be interviewed both in hospital and at home and to have these interviews audio taped as well as to fulfil the requirements under law (*Data Protection Act 1998, Human Rights Act 1998*).

A leaflet (see Appendix 3) was produced that contained all relevant details so that participation could be considered in a quiet moment with the necessary information close to hand, including the researcher's contact details if further questions or objections arose. The leaflet was produced in large bold type to ensure information was accessible to those

with poor sight. For those with hearing difficulties, the researcher spoke clearly to make lip reading possible.

Two consent forms were required, to provide proof of consent to participation in the project (see Appendix 2) and to allow the researcher access to health and social care assessments (see Appendix 4). The latter was considered necessary to understand hospital discharge packages designed for participants in the initial stages of planning this research. However, this second consent form lost its relevance as the focus of the study changed. The LREC and the Calidcott Guardian were informed of this change in writing.

The matter of 'ongoing' consent was discussed (Butler 2002). Although an initial consent may have been given, this did not commit the participant to taking part. It was made clear that participants were free to withdraw at any point should they wish to (Grout 2004), although a reason would be helpful but not required. Furthermore, withdrawal from the research programme would not in any way have an impact on the care they received (Locher *et al.* 2006). Consent and participation were at times renegotiated as a number of participants who had completed interview A decided to withdraw from the project and not complete interviews B and C (see below).

3.2.3.4 Home Interviews

As the research was designed to trace the move from hospital to supported home care it was important to emphasise the need for two subsequent interviews at home. This was highlighted to reduce the chances of participant withdrawal from the study post- discharge and to allow them full information upon which to base an informed decision. The reason for home interviews was explained in that it provided the opportunity to see how well discharge care plans were working once individuals had returned home and how, after a

period of time they were managing life with the support arrangement. Any questions were answered and a contact number was given to allow an opportunity for further queries to be answered.

3.2.3.5 Non-judgmental Approach

A non-judgmental approach is essential. It is important to be clear that a judgmental approach would represent unethical practice and would both restrict findings and provide no useful advantage to uncovering how older people experience the support available.

Keeping a reflexive research diary enabled me to view critically my attitudes and assumptions.

3.2.3.6 Non-Exploitative Research

To avoid exploitation and to fulfil moral obligations an accessible summary of research findings will be made available to participants and where appropriate, carers. This may potentially allow the individual an opportunity to discuss the findings and reflect upon the validity of the findings from their viewpoint.

3.2.4 *The end of data collection*

In grounded theory data collection and analysis are carried out at the same time, using the constant comparative method, guided by theoretical sampling. Constant comparison refers to the process of constantly coding new data and comparing them with already identified codes to develop concepts in order to generate a conceptual and saturated theory (Glaser 2001) (see Section 3.3.1).

Therefore data collection continues until the categories have reached saturation and no more new information about the emergent categories is arising from data collection (Glaser 2001). Theoretical sampling ensures that data collection is led by the emergent theory and provides the process by which relations between categories are established and

saturation is achieved (Glaser and Strauss 1967). Here, as there was restricted access to new participants, it was not clear whether saturation was truly achieved and as a result this study may be accused of 'premature closure' (Charmaz 2000). Data collection finished when access to older people leaving hospital to home from the DME was no longer available. Although interaction with the context and those experiencing discharge from hospital ended when the full series of interviews with accessed participants had been completed, data collection continued in terms of collecting theoretical and conceptual information and ideas.

3.3 Data Analysis: Uncovering Categories

Following Glaser and Strauss (1967) (see also Glaser 1998, Straus and Corbin 1998) grounded theory analysis necessarily involved the iterative process of 'constant comparison' (Glaser and Strauss 1967, Glaser 1978, Strauss and Corbin 1990). This allows issues of interest that were raised by participants in the first interview (Interview A) to be followed and further explored during subsequent meetings (Interviews B and C). This close relationship between data collection and analysis allows theory to 'emerge from the data' (Straus and Corbin 1998: 12). Analysis therefore started following the first set of interviews (Interview A). These were transcribed shortly after each interview and read in addition to notes and memos made in the research diaries.

Analysis requires "the breaking down and reconstituting" of the data available to determine underlying conceptual themes that can describe or explain the phenomena under study (Strauss and Corbin 1998: 101); here, experiences of older people returning home from hospital. In Grounded Theory this is achieved in a systematic way through the use of iterative 'coding' central to the constant comparative approach. Before the process

of coding is described, the constant comparative approach and importance of theoretical sensitivity will be discussed.

3.3.1 The Constant Comparative Method

Constant comparison is the methodological technique central to the process of developing a grounded theory and is “accomplished by constantly comparing new information with previously identified information” (Carpenter Rinaldi 1995, cited in Chiovitti and Piran 2003:429). It is the method by which data collection and data analysis are carried out simultaneously (Glaser and Strauss 1967, Strauss and Corbin 1990) and requires the use of theoretical sensitivity (Charmaz 2006). This latter issue involves being alert to emerging codes during the process of coding and using these arising concepts to guide subsequent coding at all levels and also to further data collection through the use of theoretical sampling (Glaser and Strauss 1967).

Charmaz (2000: 515) provides a view of the constant comparative method, based on Glaser’s approach (1978, 1992) that includes five aspects, which she states are:

- Comparing different people (views, situations, actions, accounts and experiences)
- Comparing data from the same individuals with themselves at different points in time.
- Comparing incident with incident
- Comparing data with category
- Comparing a category with other categories

Constant comparison must be used at every level of data analysis if it is to be effective (Strauss 1987, Charmaz 2000:515).

Strauss and Corbin (1998) suggest a series of questions the researcher should ask of the data in order to identify categories, relationships within and between categories and the central social process (core category), such as ‘What is happening in the data?’ and ‘What action does each particular happening, incident, idea and event represent?’ (Strauss and Corbin 1998).

3.3.2 Theoretical sensitivity

Theoretical sensitivity is a skill the researcher increasingly develops to conceptualize and formulate a theory by the constant comparison of data. It is about thinking in theoretical terms about what he or she knows (Glaser and Strauss 1967). “The researcher does not go blank or give up his knowledge. He goes sensitive with his learning which makes him alert to [the] possibility of emergence and how to formulate it conceptually” (Glaser 1998: 123). Different researchers, therefore, bring different theoretical sensitivities to a study (Glaser 2002). Openness and sensitivity toward data in this study was stimulated by reading literature in related fields (Glaser 1978, 2005) as suggested by the emerging categories.

3.3.3 Coding

The process of coding is defined by Strauss and Corbin (1998: 3) as the: “analytical process through which data are fractured, conceptualised and integrated to form theory” and takes place simultaneously with data collection using the constant comparative approach (Glaser and Strauss 1967). Although there is agreement that coding takes place leading to increasingly more abstracted categories, there is some disagreement about how this should be achieved. The initial approach to grounded theory developed by Glaser and Strauss (1967) has been refined and as a result, has been taken in different directions by the original authors (Locke 1996). One of the central issues of debate is how coding is achieved. Glaser (1978) recommends a more free-flowing approach, comprising of open

(substantive) coding leading to theoretical (selective) coding. Strauss and Corbin propose a more structured approach to analysis, suggesting a mid-phase (Strauss and Corbin 1990), axial coding, where a set of questions are presented as a framework (The Paradigm Model) for organising the data and informing structured categories. Glaser (1992) criticises this Strausserian approach (Locke 1996), suggesting that the proposed use of axial coding represents an overly rigid framework that reduces the creativity necessary to grasp the concepts emerging from the data (Glaser 1992); others have claimed that this framework can lead to data being ‘forced’ and more attention being focused on fitting data to these categories of axial coding than to what the data is ‘saying’ (Kendall 1999). Here a more Glaserian approach (Locke 1996) was taken when organising the data.

This process of analysis occurs at two main levels: open (substantive) coding and theoretical coding (Glaser and Strauss 1967, Glaser 1992). Although these stages are described, and reported here, as separate, they were in fact developing at the same time as data collection and on some occasions, at the same time as each other, reflecting the iterative approach to data analysis and collection central to grounded theory development, the constant comparative method (Glaser 1978, Marsh 1988, Strauss and Corbin 1990, Glaser 2001). It can be said however that at the beginning of the project more open (substantive) coding took place and by the end of analysis only theoretical coding was carried out. For clarity I will describe data analysis in relation to these two stages.

3.3.3.1 Open (Substantive) Coding

Strauss and Corbin (1998: 101) define open coding as: “The analytic process through which concepts are identified and their properties and dimensions are discovered in data”. It is the first level of analysis and is concerned with identifying, naming, categorizing and

describing phenomena by asking the following questions of the data: "What is this about? What is being referenced here?"

Each transcript was read and then coded, using the 'line-by-line' analytical method suggested by Glaser (1978, 1998). Each potential concept was coded *in situ*, that is, within the transcript, using a word or phrase arising from participants' own words to represent different experience codes. Ideas arising from notes and memos made in the research diaries and field notes taken during an initial period of observation were included as data within this process. Emerging codes (see Table 3.1) were initially collected in relation to chronological classification, that is, they were grouped together in terms of which interview and therefore which phase of the discharge process.

However, this proved unhelpful in the investigation of the central social process. Codes were then arranged in relation to their similar content, as suggested by Glaser and Strauss (1967) and Strauss and Corbin (1998). These codes and similar codes arising from subsequent interviews were continuously and constantly compared to each other to identify links, similarities and differences; in this way categories were constructed. Differences between experience codes at the start of open coding were defined in terms of 'topic discussed' to provide an initial analysis of the material.

Further data were collected, using theoretical sampling, and reviewed in relation to these categories, using the constant comparative method. Therefore, the definitions of the categories were flexible and changed to adapt to new data. Initially six main categories were identified, Making Decisions, Feelings of Independence, Matters of Concern, Living

<p>Preparing for Home and going home Change in Situation when going home, getting home and being home</p> <p>Financial concerns: paying for the newly arranged home help</p> <p>Problems with going home fear of falling 'Being a burden' No problems going home support from families Minimal support from families No Anxieties Expressed Deterioration in condition leading to an increase in self-defined care needs</p> <p>Improved condition leading to decrease needs Family organise support, and she feel this appropriate</p> <p>"We've decided that I might need help this time when I go home" No change in care needs-support provision balance Missing Hospital: 'Unsuccessful discharge' Potential feelings of abandonment They assumed a lot, but they didn't ask me"</p> <p>Complicated to get your voice heard and access information</p> <p>Feeling powerless but daughter is supportive and pro-active in getting get what she feels is needed</p> <p>Problems with communication/co-ordination</p> <p>Ask my daughter": Access to appropriate advocacy, relying on informal as a resource</p> <p>"that's what you have doctors for"</p> <p>family supportive and support good, but don't consult re home help</p>	<p>Being in Hospital Privacy in Hospital compared to home Independent with support to call on in times of crisis Immediate practical arrangements Worries about not managing once home More dependent in hospital: Happy with support from family More independent in hospital compared to others: Confusing information : given by doctors and nurses Anxiety about the medication Disagreeing with Doctors</p> <p>Getting Home Rediscovering independence</p> <p>"They say I'm not supposed to but there's no one here to tell me"</p> <p>Need for instrumental and personnel support leads to feelings of dependence</p> <p>Lonely at night</p> <p>organising support through bought in help, supported by family</p> <p>"I'm grateful for whatever help"</p> <p>experienced an adequate discharge</p> <p>Being Home Relying on others Has company but feels lonely: support increases feelings of independence Not feeling lonely Problems with 'the Warden' 'Over stepping the mark' What else is there?' Coping in a confined space at home Feeling 'Cut Off': Feelings of adequate Stages of independence Continuing concerns re feelings of dependence Living with Pain Living with grief Being Alone: Concerns about readmission Able to manage own privacy needs</p>
---	---

Table 3.1: Showing the initial grouping of experience codes that emerge from discussions with older people during a series of three unstructured interviews.

with Aloneness, Negotiating Privacy and Managing Change. However, following a process of constantly comparing experience codes and reviewing their relationship to one another initially two categories, Living with Aloneness and Negotiating Privacy, became one: 'Being Alone and Being with Others'; this category itself being subsumed within the more clearly emerging categories. Four central categories were evident at the end of this process: Making Decisions, Feelings of Independence, Matters of Concern and Managing Change (see Chapter Four, Table 4.1).

Chapter Four presents the experience codes that emerged during the open coding stage of analysis, and the data that evidence these. In addition, dimensions are suggested, in order to define the emerging categories and explain why certain properties, which are represented by the experience codes, are included each category.

The use of open coding is a key part of the constant comparative method and represents the first step in the process of inductive analysis (Glaser 2001). This process highlighted gaps and leads that shaped the collection of subsequent data. It allowed for the tentative identification of a number of emerging codes and categories which fed back into the questions asked in subsequent interviews. In addition, it represents the opportunity to develop what Charmaz calls 'sensitizing concepts', allowing the researcher to become 'attuned' to the participants' views and so limiting the potential to assume 'we all share the same social worlds' (Charmaz 2000:515).

3.3.3.2 Open coding develops

Where the initial stages of open coding led to ideas and notions of how experiences could be grouped together in relation to themes and organised by tentatively defined dimensions; the latter stages of open coding involves identifying the relationships

between experience codes that bind them together into categories, through the refinement of the dimensions that organise the properties that define each category.

In this second level of analysis, the dimensions apparent across each of the four categories, Making Decisions, Feelings of Independence, Matters of Concern and Managing Change, were more fully defined, where dimensions can be seen as “the range along which general properties of a category vary, giving specification to a category” (Strauss and Corbin 1998: 101), and properties as “concepts that stand for a phenomena” (Strauss and Corbin 1998:101). In this way, the categories represent ‘axial categories’ (Lee 1999), as they become major “constructs that the researcher selects during data analysis” (McNabb 2002:312).

As data collection proceeded, theoretical sampling was used in relation to the questions asked in two main ways; first, to refine emerging categories and so to provide a tighter definition in respect to dimensions and properties, and secondly to analyse the relationships between and within these categories in more detail. The aim was to achieve ‘saturation’, that is, when no more new codes, categories, dimensions or relationships were apparent following further data collection (Glaser and Strauss 1967, Morse *et al.* 2002, Kennedy and Lingard 2006:104) (see Sections 3.2.4 The End of Data Collection, and 3.4.5 Problems).

An initial definition of the dimensions that identify each category is presented in Chapter Four (and summarised in 4.5 Matters Arising). In subsequent stages of open coding, dimensions are developed in relation to relevant research and policy literature, to provide a greater understanding of the relationships *within* categories. In addition, the

relationships *between* the categories are explored. The defining dimensions were identified for each of the categories and an initial model was suggested that expresses an inter-relationship of these categories during the hospital discharge process. These final stages of open coding are discussed in Chapter Five (see Section 5.1 Links within Categories: developing dimensions).

3.3.3.3 Theoretical (Selective) Coding

The third phase of analysis is theoretical coding, which is the process of identifying the central social process that defines or describes the phenomena under study (Glaser 1992, Glaser 2001). The relationship between the emerging categories is more fully identified through the definition of a 'core category'; this represents the central social process that is explained by the data.

Theoretical coding involves the organisation of other emerging categories in relation to this central concept. In this way a mid-range, substantive grounded theory can be developed (Glaser and Strauss 1967: 32) and a descriptive model can be constructed (Strauss and Corbin 1998). Emerging categories and the relationships between and within these categories are more fully defined and therefore more precise (Strauss and Corbin 1998, Charmaz 2000:516). The theoretical literature is consulted, to identify the similarities and differences between concepts emerging from the data.

During initial coding and the building of categories through the constant comparative method, 'memos' were kept. These are a record of ideas about similarities and differences between the emerging categories and their sub-categories, and ideas about how the categories are related that are made throughout data collection and analysis (Strauss and Corbin 1998:110). Memos proved essential in defining the dimensions of categories, their

sub-categories and exploring the links between these. In addition, a hierarchy of the emerging categories can be defined with some categories earning their way into the final model and others being identified as more peripheral. Strauss and Corbin refer to this as 'integration' (1998:146).

The aim is to identify the core category; a category that links all the other categories and expresses the central social process under study. The core category that emerges during theoretical coding, Managing Change, must meet certain criteria (Strauss 1987), that is: "all other categories are related to it; it appears frequently; as it is analytically refined through integration with other categories, a theory with increased explanatory power emerges; finally, this central concept can explain variation in all categories and settings" (Strauss and Corbin 1998:146).

During this process of theoretical coding and integration (Strauss and Corbin 1998), the properties of the emergent analytic framework are defined. These definitions provide the basis from which to suggest a theory. The aim is that this theory expresses the central social process by explaining the relationships between categories and in turn, their relation to the core category. This can be expressed as a model (see Section 5.2.3) which describes the relationships between the categories Making Decisions, Feelings of Independence and Matters of Concern, and how they are related to the core category Managing Change. The changes older people face when leaving hospital and going home are managed through accessing support in some form, either by calling on others to help, allowing others to manage change, facing problems and being excluded. The resources available to achieve this management, and the outcomes older people have access to, are mediated through the way decision-making, gaining independence and addressing matters

of concern are organised. Different experiences of these categories are shaped by different access, play and reception of social, cultural and economic resources. This model can help to identify a number of barriers and facilitators to the process and highlight situations where older people are not receiving support as policy intends, are not autonomous and able to have their view heard or empowered by the carers that work with them, or the context in which care is received.

The 'trustworthiness' of this theory must be considered (Chiovitti and Piran 2003, Cutcliffe 2005, Kennedy and Lingard 2006). For grounded theory research, the criteria of 'fit', 'grab', work' and 'modifiability' must be met to ensure that issues of rigour have been properly addressed (Glaser and Strauss 1967: 237, Glaser 1978, 1998). These are discussed below.

3.4 Issues of Rigour: Fit, Work, Grab and Modifiability

Positivist, quantitative methodologists evaluate the academic rigour of their work in relation to notions of validity and reliability (Simmons 2001, Chiovitti and Piran 2003, Kennedy and Lingard 2006). In qualitative research this is replaced with concerns for trustworthiness. This is constituted by three central concepts: credibility, generalisability and auditability (Lincoln and Guba 1985, Chiovitti and Piran 2003, Cutcliffe 2005). However, within the Grounded Theory paradigm, the credibility of research is judged using four main criteria: 'fit', 'work', 'grab' (or 'relevance') and 'modifiability' (Glaser 1992). A grounded theory is never right or wrong, it just has more or less fit, relevance, workability and modifiability, and readers are asked to judge its quality according to these principles.

3.4.1 Fit

Lomborg and Kirkevold (2003) have pointed to the criterion fit as most important for evaluating the validity and truth of the grounded theory. 'Fit' is a measure of how well the grounded theory expresses the data, that is theoretical categories must arise from the analysis of data and must explain the data (Glaser 1978, 1992), with any existing categories 'earning their way' into the theory.

A central issue here is that categories must not be forced or selected out of preconceived understandings of the phenomena studied (Glaser 1978). Instead they should be generated systematically from data using constant comparative analysis which requires the continual fitting and refitting of the categories to data.

To reduce the tendency to fit data to preconceived understandings and assumptions, a reflexive approach was taken and arising issues considered. The literature was searched using a mixture of 'snowballing' (Bowling 2002) and structured searches, only after the first stages of open coding had been completed and was guided by codes and categories arising from analysis of the data.

Fit has a further dimension in that if a grounded theory is carefully induced from the substantive area its categories and their properties will make sense and be recognisable as expressing the central social process by older people themselves as well as practitioners and researchers in the area (Locke 1996, Glaser 2002).

In the final level of analysis, categories are linked together to provide "a dense and parsimonious theory" that fits the substantive area (Glaser 1978, 2001). Therefore, fit is

more fundamental to a theory than the other three criteria of work, relevance, and modifiability.

3.4.2 Work

If a grounded theory works it will explain the major variations of behaviour in the area, with respect to the processing of the main concerns of the subjects. Therefore a grounded theory must be able to explain what happens in the data, predict what will happen, and interpret what is happening in the area studied (Locke 1996). Workability is related to how well a theory accounts for the way in which participants solve their main concern (Glaser 1992, 1998).

The use of simultaneous data collection and analysis which under-pins the constant comparative method aims to ensure that theoretical constructs arise directly from the data (Glaser and Strauss 1967, Strauss and Corbin 1998). This process requires that the arising concept is 'tested' against subsequent data, which should ensure that the arising theory reflects the empirical reality.

3.4.3 Grab

The third criterion concerns relevance. If the grounded theory fits and works, it has achieved its relevance (Glaser 2002). Therefore, a theory is relevant and has good grab for participants and practitioners in the substantive field when it allows the core problems and processes in the area to emerge (Locke 1996).

3.4.4 Modifiability

The fourth criterion is modifiability; the theory should be readily modifiable when new data present variations in emergent properties and categories. A substantive grounded theory has only partial closure because new ideas and more data can modify the theory.

Modifiability is therefore an ever-ongoing process, and all grounded theories have potential for further development (Glaser 1978).

3.4.5 Problems

The design of this project may be considered problematic in a number of areas which will be reviewed in full in Chapter Six. However a central issue related to practical aspects of data collection and data analysis is that of limited resources, in terms of time, access to participants and researcher experience. As a result only a certain ‘window of opportunity’ was available for recruiting and interviewing participants. In addition, the standard of project management and the level of sophistication of data collection and data analysis reflected my status of ‘learning on the job’. Although topics and issues within the analysed categories were raised by more than one participant and new issues which arose during all interviews were included in the analysis, it was unclear whether saturation was achieved (Strauss and Corbin 1998). This may threaten the ‘fit’, ‘grab’ and ‘workability’ of any emerging core category and the model that describes it. One solution would be to increase the amount of data collected by interviewing a greater number of older people leaving hospital for home and/or interview each participant more often until it is clear that saturation is complete.

I was unable to return to the participants of this project to complete the process of final verification due to the length of time that data collection and analysis had taken (Coyle 1999: 104) however, workers at the local Age Concern complex were consulted about the aims and design of the project and project findings were discussed with three older people who found it convergent with their experiences. As one noted, everyone seems to have a tale to tell about difficult experiences of either being cared for or caring for another. Reviewing the emerging model and research findings through focus group discussions

with older people, carers and practitioners would have provided an opportunity to check the 'fit' and 'grab' but is beyond the resources of this project.

3.5 Who's Who: Who's Who: An Outline of Individual Situations

Throughout this project I have drawn upon the experiences of 12 older people who allowed me both into their homes and into their private experiences. Before presenting an analysis of the collected data it is important to provide individual outlines of those who took part, to place them and their experiences as central to this project and in an attempt to do justice to their trust and present them as far as possible as whole people. Therefore I have included details about their past as well as their present situation where possible. The quotes come from interviews across the series, during three stages: *preparing for home* (Interview A)- while in hospital; *getting home* (Interview B)- during the move from hospital to home and including the first week settling in, and *being home* (Interview C)- after eight weeks at home. In order to protect the anonymity of participants, carers, friends and relatives all their names have been changed (*Data Protection Act 1998, BSA 2002*).

3.5.1 Mrs Andrews

Mrs Andrews is 82 years old and has lived in the city all her life. She was the mother of one son and, as a young woman, worked in the fruit market before she was married. During the war her husband was away, and she had to care for her son alone, as well as work in the local grocery shop. She describes these as 'exciting times', despite the hardships she faced raising a child alone in war-time Britain:

Mrs Andrews: I had a grocer's shop job... I don't know if you ever knew 'em... did you ever know em? 'Cousins' at Maypole have you ever heard of them? We used to be butter patters in them days...there int such a thing nowadays

Clare: Did you do that for long?

Mrs Andrews: Ohhh yes... right through the war.

Mrs Andrews: Oh yes, I was in a grocery shop... there was all those coupons to count and everything... it was nice... we used to have the old men at one end on one side... 'cos they was too old to go to war... and the others on one side:

Clare: Was your husband away?

Mrs Andrews: Oh yes he was a captain in the merchant navy... he was ... we had some fun like as well love it wasn't as if we didn't have some laughs as well 'cos we did. Look at them all now... I think if there's a war now God help us all with that lot (laughs).

Mrs Andrews had been living alone for sometime:

I've been on my own twenty years now... and I'm going to be truthful with you... I was too bloody windy to get another 'cos he was a good fella (Laughs). I thought if I got another one and he wasn't a good one then... I'd be fighting... and that's why I remained single.

Mrs Andrews' son died of a heart attack 20 years previously, in his mid-forties. She had a younger brother who lived in a small town 20 miles away who provided some informal support:

My brother's very good. He lives in [a local town] and he comes every Thursday to me, takes me for my pension, takes me for my shopping... I buy as much as I can love so that I don't run short.

Her brother was there when she was discharged and continued to provide a low level of support and to take her shopping weekly.

Mrs Andrews lived in a warden supported complex of flats, but received no direct help from the warden:

Well she don't look after us. You look after yourself... she was a sister... I don't know what the hell she's for... she used to be the sister of a ward... she said: 'I don't look after you, you look after yourself' and I have done ever since.

Pre-admission Mrs Andrews had a home-help service but had not been satisfied with her standards of work and had asked her to leave:

Clare: Doesn't anyone come in to help?

Mrs Andrews: Oh I did do... I chucked her out... I'm not paying for that for nowt.

Post-discharge Mrs Andrews had some trouble with getting the help she felt suited her. On discharge hospital health care staff had restarted her home-help service, arranging for a formal helper to visit her once a day. However, not happy with the service Mrs Andrews requested a change in staff. By the third interview in the series (C) she had found a home help that suited her, with the help of the domiciliary care service, but her home-help was soon to leave the job and she faced the prospect of going through the whole process again.

Mrs Andrews lived in a bungalow designed for older people and no further adaptations were made post-discharge. Mrs Andrews had used two sticks to mobilise; post-discharge, she was given a walking frame by the hospital.

3.5.2 Mrs Branson

Mrs Branson is 83 years old and lived alone. She talked about her work when she was younger:

Mrs Branson: I had to work 'cos I was left a widow at 46.

Clare: That's young... what did you do?

Mrs Branson: I worked in a fruit broker's office down [a local] Street ... I learnt all the bad language... I learnt all the latest words [both laugh]... they can come out with all sorts now and it just goes over the top of my head... I do say 'do you mind' but ... er...

Mrs Branson lived in warden-supported housing, although she did not have an easy relationship with the warden and felt she received little support from her. However she did feel supported in some ways from the other paid members of staff, such as the hairdresser, and those that run the lunch club within the flat complex, which she had attended pre-admission. She also had organised to have a cleaner once per week for half an hour of cleaning and half an hour of ironing.

Mrs Branson had a supportive family, but they did not all live nearby, nor were they always able to come and visit her. Her oldest daughter, who lived closest to the city, was her main source of informal support:

I've got three daughters and a daughter-in-law but my daughter-in-law lives in Suffolk so I don't often see her... but my eldest daughter bears the brunt of it bless her, she's a teacher. My middle daughter comes in the middle of the week... or has been doing while I've been in here [hospital], just to see me and talk to me, and my youngest daughter is also a teacher but she's got a partner and has suddenly produced again, so now I've got eleven grandchildren.

Pre-admission, Mrs Branson had some practical help from her neighbour, although she did not feel she could necessarily rely on this help post-discharge:

My next-door neighbour has been very good but whether she continues to be good I don't know... but I think that she'll be helpful in so far as fetching me some shopping if I want it...otherwise my daughter does all my shopping.

Mrs Branson lived in a purpose-built ground floor flat. She had lived there for 14 or 15 years, and found it comfortable and suitable to her needs. Pre-admission, Mrs Branson managed to mobilise with the help of either a stick or beta-frame, depending on what she felt appropriate at the time, however, after re-assessment by the hospital physiotherapy team, Mrs Branson had been advised to use a roma-trolley around her flat, as this has a basket and flat area to carry hot drinks and so on around her flat. Post-discharge however, anxiety about the possible exacerbation of her condition led to reduced mobilisation, lack of confidence and a restricted social life.

Other equipment needed had already been organised by the Institute for the Blind and Mrs Branson's family; for example a microwave oven to reheat frozen food, a sit-down shower and a magnifying lens for the television. Mrs Branson received a frozen meal service, suggested by the hospital on a preceding admission and organised by her family.

Mrs Branson was admitted this time to hospital for acute angina and possible myocardial infarction ('heart attack'). She had been admitted previously with the same problem. On this admission she was hospitalised for a period of a month. Mrs Branson talked about her experience of being unwell and being admitted:

Half past nine at night I was watching the television... and I thought I don't like this I'm going to switch it off and I'm going to go to bed... as I went to bed I thought 'Who's that sawing wood?'... and it sounded like [pants]... it was me breathing... by the time I got to the bed and pressed the button... and I said to the man 'Please help me'... and within seconds he said 'Is your front door open darling? And I said 'Yes I can open it I think'... and he said 'Get and make sure it's open and somebody will be there in a few minutes'... and they were... but in the meantime the ambulance man had locked my front door for me... and I don't remember coming here.

3.5.3 Mr Charles

Mr Charles was an 82 year old man, who lived alone since the death of his wife five years previously. As a young man he worked as a shopkeeper on one of the many busy main streets in the city, selling "everything and anything". He started working as a shop boy, delivering groceries, and worked his way to shop keeper. He remembered his time fondly: 'we often would get together, the other lads working down [local] Road'.

Mr Charles married in 1943 aged 22, a war time marriage to a girl he had known since childhood. They had four sons, two of whom have died, and he was no longer in touch with his other two sons, one of whom lived in Australia.

Mr Charles was initially admitted to hospital following complaints of stomach pains. He was found to be constipated and although this initial problem was resolved, staff were concerned with Mr Charles's ability to look after himself adequately and his hospital stay was extended while support at home could be organised. Mr Charles had chronic

problems of emphysema and cancer of the prostate, for which he was receiving on-going medical intervention.

Pre-admission Mr Charles had a care assistant visit three times daily, morning, lunchtime and evening. He also had a home-help come in weekly to support him by carrying out domestic duties, such as housework, shopping and laundry. Mr Charles had no family living nearby, until recently when his niece had moved into the area. Although they were not a close family, Mr Charles's niece (Pam) became involved in his care as a result of seeing her uncle in a difficult situation.

Pre-admission, she had little to do with his immediate care. Sometimes she worked away and was not always able to help her uncle, although she did talk to him on the phone on a regular basis. On admission and in the planning of his hospital discharge, she helped negotiate, co-ordinate and organise support provision for his return home. However, Mr Charles was discharged by the hospital at a time when Pam had informed the staff she would be away on business. On her return she realised her uncle had been discharged and visited to find that services had not been restarted and Mr Charles had been left at home without support for three days. She phoned his GP, who called an ambulance and Mr Charles was readmitted to hospital suffering from dehydration and breathlessness.

A formal package of support was again planned, but Mr Charles's niece, Pam, did not feel that she could rely on formal help. She decided to provide his personal care herself and did not take up the offer of care assistant visits three times daily; however, she accepted the offer of a regular home-help to continue as before, although on a three times a week basis. Pam visited Mr Charles twice daily after his second discharge, morning and

evening. Mr Charles did not feel entirely comfortable with this arrangement and Pam had to change her work pattern, which added to his concerns.

Initially consulted (on his first preparation for discharge home Interview A) about the support he was to receive at home:

... She [nurse] did ask so I told her.

On the second discharge he was offered little choice:

No one really asked me what I thought about going home. They assumed a lot, but they didn't ask me.

By week eight, Mr Charles was receiving a formal care assistant once daily, at lunch time, with his niece still providing support morning and evening, and a home-help visit three times weekly.

Mr Charles lived in a partially adapted ground floor flat. He had access to the toilet and to an adapted bath, although his extreme breathlessness and lethargy meant he found washing himself wore him out, and left to himself, he did not attempt it. Mr Charles received a frozen meal service although he had to be encouraged to prepare food and rarely did this himself, relying instead on his niece, care assistant or home-help. He mobilised with a beta-frame, although he found this laborious as he was often breathless. Mr Charles had a 'life-line', paid for by his niece. This is a fast response support service that can be initiated by activating an alarm worn around the neck. In this way emergency help is available in a crisis.

3.5.4 Mrs Heathfield

Mrs Heathfield was an 83 year old woman who lived alone. She had two children: a son who lived with his family in Manchester and a daughter in Leeds. Both visited on occasions. Mrs Heathfield generally organised her own care and support:

Well they [family] came while I was in hospital for two days and stayed the night, now I don't know when I'll be seeing them, perhaps a fortnight's time.

Mrs Heathfield had paid help from a near neighbour, Peggy, an arrangement she organised and paid for herself. Peggy helped with most day-to-day care needs, such as shopping, making sure Mrs Heathfield had food to hand for her meals, posting letters, collecting medication from the chemist, giving lifts to and from hospital out patients and GP appointments. Peggy was also a support in a crisis, and helped Mrs Heathfield by calling for the GP when Mrs Heathfield was in need on this hospital admission. Peggy represented a lifeline and Mrs Heathfield felt she would be unable to remain independent without her support:

I met her [Peggy] when she moved in near me... she's very good and I couldn't get along without her... some of them there think she's a bit bossy but she helps me and I couldn't manage there if she didn't.

... but without her I couldn't... I couldn't cope you know... I'd have to get help from outside which isn't the same is it.

Mrs Heathfield had a frozen meal service arranged by her daughter and paid for by Mrs Heathfield. She also paid for a weekly help with the housework, laundry and to provide other domestic support. She felt supported in her home situation:

If I do have any trouble I know there's people I can ask... I don't know where I'd be if I didn't have that.

Mrs Heathfield lived in purpose-built sheltered accommodation adapted to her needs that she bought and paid for herself:

I'm lucky. Those flats have everything where you might need it... I have a seat on the bath so I can get in and have a good wash.

The flat complex was 'warden supported' and formal semi-professional carers organised and run social clubs, such as the coffee mornings which she attended, to socialise and meet up with friends who live in the same complex. To help her mobilise safely Mrs Heathfield used a beta-frame and a roma-trolley. She also had organised and paid for, a magnifier for her television and an adapted phone with large buttons and an amplifier, as she had both poor eye sight and was hard of hearing.

Mrs Heathfield was admitted to hospital during the night as a result of increasing pain in her leg. She was diagnosed as having phlebitis (inflammation of the veins) in her legs and received anticoagulant therapy, Heparin initially, then stabilised on Warfarin before her discharge home. She had her first heart attack when she was 80 years old and a second attack about three years ago, and this had reduced her confidence in going out:

I take things easy now, but when I do go out I'm alright for a while but not too long. I like to sit down and get my breath back and you can always feel a twinge somewhere. You have to live around it really.

Mrs Heathfield was also taking diuretics and this combined with her slow mobility led to problems in managing continence whilst in hospital. Once home however she found it easier to manage as she had easy access to her own toilet, so did not have to walk a long way nor wait until the toilet was free:

... At home the toilet's nearby which is a help because I'm on water tablets and it's quite a way down the ward to the toilet here.

By the time you got the urge and I got down there [to the toilet]... quite a few times I dirtied myself... which is distressing... I couldn't help it but I couldn't make [it]... and then sometimes somebody's in the toilet and you can't get in... I didn't like that at all.

Mrs Heathfield also contracted diarrhoea and vomiting (*Clostridium difficile*) whilst in hospital which, at times, compromised her attempts to remain continent. Due to her congestive cardiac failure she experienced breathlessness on exertion, which further reduced her ability to mobilise, especially outside, and had reduced her confidence in walking and increased her anxiety about falling. She also suffered from arthritis which had been a problem for several years.

3.5.5 Mrs Hodges

Mrs Hodges was an 84 year old woman, who had lived alone for a number of years.

Before her marriage (in 1946) she worked:

When I left school I took shorthand and typing course and worked for a district evaluator as a secretary ... and I really enjoyed it... we were assessing war damage.

Mrs Hodges had two children. Her daughter, Jane, lived with her family near Manchester and ran her own business; her son, John, lived with his family near Blackpool, he also worked. Mrs Hodges' family were supportive and her daughter was actively involved in organising support that suited her mother's needs and wishes. Both children visited regularly, on alternative weeks. Post-discharge, both children were present to ensure all

the necessary arrangements were made, and during her first week or two home they visited more often:

She [Jane] was here yesterday from nine 'til about three... John comes on the weekends and she comes every week at the moment.

These visits subsequently returned to the usual pattern. Mrs Hodges had a number of friends who live nearby, especially Vera, who lived next-door. Vera visited on a regular basis, but had problems herself with mobility. Mrs Hodges therefore had some help "but mostly I manage on my own".

Pre-admission Mrs Hodges had a daily carer who came in the morning and helped with laundry and housework, sometimes shopping for essentials. Post-discharge, the carer attended three times daily for the first six weeks home (continuing care package), then reducing to a daily visit.

She had a frozen food service that provided her with her main daily meal organised by her daughter. She did cook for herself but post-discharge felt she would use the frozen meal service until she was feeling strong enough to return to cooking. Mrs Hodges paid for both the frozen meal service and the carer.

Mrs Hodges lived in a purpose-built bungalow that had a walk-in shower and enough space around the toilet to manage with her frame. She used a walking frame (beta frame) to move around her home:

It's a comfortable house the one I've got at the moment, everything's to hand.

Mrs Hodges was admitted after a period of extreme breathlessness and diagnosed with a chest infection, for which she received antibiotic and oxygen therapy during her four week hospital stay. She had arthritis in her knees and found walking painful when her arthritis was exacerbated.

3.5.6 Mr James

Mr James was a 94 year old man. Mr James married and had three children, He worked as an accountant before he bought and ran a corner shop. After serving in the Navy during World War Two, he returned to his business. His shop was compulsory purchased during the redevelopment of the city in the mid to late 1970s. Mr James moved with his wife to the newly developed estate, where he lived until after her death in 2001. He then moved to a ground floor, purpose-built warden supported accommodation near his son, Robert. He had an adapted bath, so he was able to get in and out of it himself. He received a frozen meal service and enjoyed organising his meals himself. Although he ate very little, he ate regularly and was conscious that his diet was important and was reflected in the way he felt physically.

Mr James learnt to drive in his sixties, although following a near crash his son drove the motability car. He also took up bowls during his sixties which he continued to enjoy. He was a very sociable man and took part in clubs and groups run in the day room by the warden and staff. He had also instigated a bowling club within the complex. Mr James had heart failure and regularly experienced angina and breathlessness. He was admitted after suffering extreme angina, not resolved by sublingual spray. He was partially deaf, and used two sticks to mobilise around his home. If he took it slowly, he could manage most of his personal care needs at home, with the purpose-built bathroom. Mr James had

daily support from his son, Robert and at least weekly visits from his grandson, Bob. He felt supported by the warden and other staff that work within his housing complex. Mr James had a weekly help who carried out domestic duties, such as laundry, cleaning the bathroom and general housework.

3.5.7 Mrs Manning

Mrs Manning was a 94 year old woman. She married in 1933 and moved to the city the same year. Mrs Manning's husband died two years previously, aged 92 years old, after sixty seven years of marriage and she continued to miss him. They had two children and lived together until World War Two started:

My husband always used to say... 'Don't say that [you don't work] because you have worked you've looked after our home and our two children and during the war... you see I was on my own with Judith [daughter]. I was on my own you see... so you know it wasn't... and of course eventually my husband he had to go... he was called up eventually. He was a captain in the army.

She had fond memories of raising her children and the support she found in her friends:

Mrs Manning: When I think back we had a wonderful spirit about the way we looked after each other and we used to go pram pushing every afternoon all four of us

Clare: So the women clubbed together

Mrs Manning: Oh yes... oh yes we did... and there was a tennis court called Springhead... it wasn't very far from us so we used to do this walk down to Springhead with the tennis rackets and [laughs] push the prams all on the line and then we used to play tennis. In a way I think back and I have had a wonderful life

Clare: You have been very active

Mrs Manning: Oh yes, I have

Clare: Do you think that's the secret to why you're so with it now?

Mrs Manning: Possibly, I don't know, no idea, but when I think back I feel I had wonderful life, I've had some wonderful friends... yes I'm lucky and I count my blessings every night, I really do.

She liked to take care of her appearance:

Normally, I mean my hair's all a mess 'cos I've been so hot but... no... I mean normally I'm very particular about my face, getting my face made up but, I'm used to having nice things too, so that really I feel quite, well but when you get to my time of life you've got to be really careful.

I go to the hairdressers every week and I have a taxi with another friend we both go at the same time and then get a taxi back again.

Mrs Manning was an active, sociable woman, with a large family who lived nearby. She had had a busy social life in the golf club and as part of the church; she continued to attend Christmas functions:

I go to the church functions... I go if they have a Christmas tea party... you know they send me an invitation and I go along with a friend... we join all the elderly ladies because I am now really [laughs].

Mrs Manning described how she came to be in hospital:

I went to bed one evening and er... I don't usually go 'til about midnight because... if I've had a long day... I don't really want to go to sleep so I don't... anyway... I

suppose... I got undressed and went to the bathroom and did all my ablutions and...

then I suddenly started feeling... 'Oh I feel a bit tight'... tight across the chest.

Mrs Manning lived in a terraced house, with an upstairs toilet and bathroom. She used a roma-trolley to mobilise and enjoyed time in her garden, although she had found this limited since her recent illness as she was afraid of falling. Mrs Manning felt 'washed out' and 'weepy' after her return home, and planned to take things easy. Her daughter and son lived nearby with their families and visited her weekly as a rule, although following her discharge home from hospital they spent more time with her for the first week or so. She felt supported by family who organised her care at home and were also close to hand in an emergency, for example, it was her daughter she rang when she was feeling ill and her daughter who called the ambulance. Her daughter also provided daily help, such as organising meals:

She does my meals and puts them in the freezer and I have to just warm them through... although she comes in during the week when she can but mostly I see her on weekends and the rest of the family you know... they all come over on the weekend... but they phone up to see I'm alright.

The hospital staff and Mrs Manning's son and daughter organised for her to have continuing care, involving a six weeks provision of a daily carer. Mrs Manning paid for this service as she was not entitled to means tested social care. The daily carer service stopped after six weeks, and became a twice weekly service.

Mrs Manning accessed equipment through social services and paid for all the equipment she used. Initially, pre-admission, Mrs Manning was using a roma-trolley to help her to

mobilise more easily. Post-discharge, she had the additional aid of the beta-frame, recommended by the hospital physiotherapist. Although Mrs Manning lived in a terraced house with an upstairs bathroom and toilet, she had handles placed to give her added support whilst climbing the stairs. A further adaptation previously made to her home was the seat in the bath and hand rails around the bath to help her get in and out, but also to provide her with confidence while bathing.

Initially, Mrs Manning felt too weak to manage the stairs; this problem was overcome by her daughter who borrowed a commode and arranged the house so Mrs Manning was able to sleep downstairs. The commode was returned after six weeks and Mrs Manning began to use the stairs, although this was difficult for her and she had to 'set off early'; she felt she had no choice but that she would manage.

3.5.8 Mrs Selby

Mrs Selby was an 89 years old woman. She moved to the city with her husband in the late 1990s, to be nearer her children. She lived with her husband, but their four children, two sons and two daughters lived nearby. Mrs Selby was included in this study despite not 'living alone' as the decision to not include her case would contain an underlying assumption about the support she gets in her day-to-day life; that is, although she may live with her husband it cannot be assumed that he provided her with the support she felt appropriate.

Mrs Selby had been disabled for several years. She was admitted to hospital following extreme breathlessness and angina. She had been admitted with this problem before and had a coronary artery bypass graft (CABG) five years earlier. Her husband had looked

after her at home. Although he was getting older and had health issues himself (his “knees are bad”) he still wished to support his wife, especially with her personal care. Their children were supportive of their father in his wishes to look after his wife.

The oldest daughter, Sarah, organised and co-ordinated the support needed by both her father and mother. Mrs Selby felt she could rely on her daughter to make appropriate arrangements and trusted her to make decisions on her behalf. Sarah or her sister took their father shopping and ensured their parents had the supplies they needed. Mr and Mrs Selby did not have any formal support whilst they were at home. All the support they received was informal and managed between their children, mostly by Sarah. On discharge home they were offered the support of care assistants and home help, but this was declined as Mr Selby wished to continue caring for his wife, and their children continued to be supportive of this.

Mr and Mrs Selby moved to a newly built bungalow that is adapted to their needs. They had lived there for about seven years:

They'd just finished building it when I moved in ... everything is brand new you know... and I've got a cord you can pull if you want assistance or anything... you've got everything there at hand and its very roomy, plenty of space for the chair... I've nothing to walk or anything to do really... you can go from one place to the other without any bother.

Pre-admission, Mrs Selby used a stick to mobilise, but once home she used a beta-frame, which helped her feel more confident about moving about. However, she generally used her wheelchair if she went out of the house.

3.5.9 Mrs Trent

Mrs Trent was an 84 year old woman. She had lived in the city all her life. She moved to her current home after the death of her husband in 1992. She then lived in a bungalow and was able to manage all her own personal care. She mobilised with little aid. She did her own shopping, with the support of her daughter, and was able to visit her sister who lived around the corner. She also had a 'man-friend', an 82 year old man who lived close by and they visited each other two to three times a week and keep each other company. She enjoyed social company but, although pre-admission, she was a member of two clubs, going to each on alternate weeks, this pattern did not restart after she returned home.

Mrs Trent's daughter, Mary, lived nearby. Mary had an ill husband, but she brought her mother's meals and made sure she ate daily, leaving food easily accessible so she could help herself as she needed. Mrs Trent independently visited her sister every week and had other friends who lived close by.

Mrs Trent was admitted to hospital with stomach pains; a problem she had experienced before. She was in hospital for eight days. During the preparation for her return home, the doctor told her daughter and son-in-law that she must do no 'heavy lifting' and a carer service was started. However, Mrs Trent worried about paying for the service.

3.5.10 Mrs Weeks

Mrs Weeks was a 92 year old woman who worked in London as a financial secretary before she retired at 65 in 1971. Mrs Weeks' first husband, Henry, died of a heart attack in 1964. She remarried in the mid-seventies. The couple moved to a bungalow in the outskirts of the city when her second husband, John, was suffering from stomach cancer.

They moved to the area to be near John's son, Mark. John died three years after their move and Mrs Weeks continued to live in the bungalow where she lived independently and pre-admission was able to manage her housework and personal care tasks:

We moved up from London to be near [stepson] and bought it [house]. It's just round the corner so he could come round every day. It's small but I have everything where I need it now.

Mrs Weeks' step-son, Mark, lived nearby with his sick wife who he cared for and was there in case of emergencies. They did not have an altogether happy relationship and there was tension between the two. Mark took Mrs Weeks shopping but did not allow her the time she needed as she saw it and she was only able to 'get the basics'. Mark was also available to help Mrs Weeks with house repairs and had recently mended her fence, although she complained that he charged her for this help.

Apart from Mark, Mrs Weeks was friendly with a neighbour, Edith, who visited her on a regular basis, again there was some tension in their friendship and Mrs Weeks did not always feel supported by Edith. However, when Mark went away, it was Edith's daughter that came to make sure Mrs Weeks was managing.

Mrs Weeks suffered an injury to her right arm in 1960 and it had been 'weak' ever since. Over the last decade it had become swollen and painful and her pain was managed with Ibuprofen as prescribed by her GP:

I've had this for a long time, since 1960. I fell off the ferry... we used to go and visit Henry's mother, that was my first husband, We used to go every Saturday on the ferry and one time, the time I did this I was standing at the end of the boat waiting to get off

and someone lowered the thing too early and I kind of slid... but my arm got caught that's what saved me really you know, this arm saved me from going into the water, and it got caught and stopped me sliding, well they got an ambulance and Henry said he was terrified when he saw me slide. I was all bruised up here and along here [indicates right side and shoulder and back] Oh it was terrible dear and I went to hospital and they said I'd be badly bruised. Well it's never been right since, you know, it's weak, it's got no power, it can't hold things like this one [raises left arm] and it stayed swollen. John [second husband] said I should have sued but it wasn't like that then. Henry said 'Why take money from tax payers, leave it for someone in need'.

Mrs Weeks was admitted to hospital when her right arm had become very painful and the swelling had increased. Pre-admission, Mrs Weeks managed her own domestic duties. After her return home, her step-son organised a daily carer, Sally. Mrs Weeks lived in a bungalow; minor adaptations were made to her bathroom in that bars were put around the bath to help her get in and out. However, due to the problem with her arm, she was unable to use the bars, so she strip-washed daily instead.

3.5.11 Mrs Westerby

Mrs Westerby lived in an 'old people's' bungalow, near one of her daughters and one of her sons [Barry]. Both these children were involved with their mother's care and helped her at home, through regular visits. Another son worked on 'the ferries' and visited while he was in the city, but was unable to give regular support. Another daughter looked after her husband, who had Alzheimer's. Three years previously Mrs Westerby lost one son (in April) and her husband (in May). One daughter lived in a local town and was married to a "money lender" and she had not seen her for eleven years.

Mrs Westerby was admitted to hospital as a result of extreme breathlessness, not a condition she had experienced before, although she had had a severe heart condition for a number of years. She received support from her eldest daughter, son and daughter-in-law, who lived nearby and were able to help. They had organised a routine between them, which ensured that Mrs Westerby was visited daily by her family, as well as being available on the phone at any point. For example, when her daughter was at work in the evenings, she felt she could call on her son and daughter-in-law for any help she might need. Mrs Westerby had a care assistant, who she paid for, who came every day, at 8.30 in the morning on week days and her daughter-in-law helped her at the weekend. Pre-admission, Mrs Westerby used a zimmer frame, but once home had bought a roma-trolley as suggested by the ward physiotherapy team.

3.5.12 Mrs Woodward

Initially, Mrs Woodward returned to an adapted home, which she had shared with her husband and adult daughter Tess, who had learning, vision and auditory disabilities. Mrs Woodward was admitted to hospital in the days following her husband's death.

Mrs Woodward had complex support needs; she was overweight, had diabetes and was intolerant of fat and therefore had specific dietary and care needs. Her weight and general weakness led to restricted mobility, she was unable to climb stairs and mobilised, using a roma-trolley, for very short distances. She faced continence issues and was commonly doubly incontinent. These factors combined led to a need to have easy access to toilet and washing facilities.

Mrs Woodward was admitted to hospital with pancreatitis, an issue that was addressed during her hospital stay. On discharge she returned to the care of her family of ten children, with the majority of her care being provided by two of her daughters, Paula and Carol, who also worked as care assistants. However, in reality Tess was the only person at home and the informal arrangements, upon which Mrs Woodward had previously relied, were in a state of flux, following the death of her husband.

Within a month of her return home, the practicalities of informal support became unmanageable and Mrs Woodward and Tess moved to the un-adapted home of another daughter. The lack of adaptations restricted Mrs Woodward to the downstairs areas and compromised her attempts to remain continent. The small size of the house led to Mrs Woodward and Tess sharing the living room as a bedroom, as well as this being the area in which Mrs Woodward used the commode and met her hygiene needs through “strip-washing”, in addition to functioning as the main social area of the house.

Within a month Mrs Woodward and Tess again moved to stay with her youngest daughter and her partner. Some attempts were made by the family to find sheltered accommodation that would support both Mrs Woodward and Tess, but no appropriate accommodation could be found despite self-referral to the local council housing department for guidance and requests for help made to Mrs Woodward’s GP.

Following yet another move which resulted in a disrupted stay with her youngest son, Mrs Woodward’s seventh daughter (Susan) took her mother and sister in, despite living in a small terrace house, already occupied by Susan, her partner and their three teenage daughters. Susan complained to the council with regards to the inappropriate nature of the

accommodation they were offering, and was advised to apply for a grant to extend and adapt her family home. This application led to an occupational therapy assessment, that confirmed that Mrs Woodward's needs included an accessible bedroom, toilet and washing facilities. These adaptations took eighteen months, during which time, Mrs Woodward and Tess again shared the living room as a bedroom and Mrs Woodward used the area to strip-wash and used the commode.

3.6 Summary

In this chapter the project design has been explained, issues surrounding data collection and analysis have been explored and a number of methodological considerations have been discussed. Finally an introduction to the older people who took part has been made. Chapter Four focuses on the presentation of the emerging categories and the experience codes collected in relation to these during open coding, and concludes with the initial stages of open coding.

CHAPTER FOUR

GOING HOME: THE FIRST LEVEL OF ANALYSIS

A range of experiences were expressed and discussed by older people. Chapter Four presents the experience codes that arose during open coding and defines four emerging categories with reference to tentatively suggested dimensions.

Open coding, the first level of analysis, is defined by Strauss and Corbin (1998: 101) as “the analytic process through which concepts are identified and their properties and dimensions are discovered in data”. Experiences discussed by older people during interviews were identified throughout the data collection process, using the constant comparative method (Glaser and Strauss 1967, Glaser 1978, Marsh 1988, Strauss and Corbin 1990, Glaser 2002). Four categories emerged during open coding, as experience codes were collected in relation to the following topics: Making Decisions, Feelings Independence, Matters of Concern and Managing Change. The dimensions apparent across each category and properties represented by the emergent experience codes were identified.

The aim of this chapter is to report the results of open coding by presenting the evidence for each of the experience codes that lie within the four categories and suggesting dimensions that explain the properties of the experience codes. In this way the categories can be defined; a process that is completed in Chapter Five as these categories are further refined in relation to research literature, local and national policy and practice guidelines and codes of practice.

In the final section of this chapter, the dimensions and properties are summarised. Chapter Four therefore is a first step towards analysing the experiences of returning home and receiving support discussed by older people and developing a model that describes the complex experiences arising during hospital discharge and allows an identification of the problems older people face during their experiences of receiving support.

During the initial analysis all experience codes are given equal weighting and many are developed from *in vitro* codes. As analysis and data collection continued some experience codes merge and subcategories began to emerge as each category became more defined. Table 4.1 below provides a summary of this level of analysis and this is reflected in how the experiences codes are organised in Chapter Four. The data is presented in such a way as to portray a snap-shot of the analysis process at a point where the dimensions of each category begin to develop.

Making Decisions	
Planning	'If I do have any trouble': Active in Decision-making 'We've decided I might need help': Family supports decision-making 'My children will see to me': Planning managed by family That's what you have doctors for': Use of formal support Planning made difficult by the actions of others 'He's coming... I don't know when': Problems with Formal Professional staff 'As far as she's concerned': Problems with Formal semi-Professional staff Feelings of exclusion from decision-making 'He didn't tell me': excluded by doctors 'No one really asked me': Non-inclusive Decision-making 'Why should I?' Disagreeing with Doctors
Enacting	'I think I can manage': Active participation in transition 'My daughter brought me back': Transition managed by family 'They remembered me when they got to the end and there was a meal left': Problems with transition
Reviewing	'Peggy helps me': Leading the decision-making 'I'm not having that': Active in decision-making 'We're managing fine': Decision-making supported by family 'They say I'm not supposed to': Adapting available support 'Over stepping the mark': Limited by the actions of formal support

Feelings of Independence	
Coping in hospital	<p>Feelings of independence in hospital</p> <p>'I see people worse off than me': Recognising Independence</p> <p>'Now I do for myself': Rediscovering independence</p> <p>'He comes in to help me': Independence supported by family.</p> <p>'Using your own': Feelings of restricted independence in hospital</p>
Consuming Support	<p>'They'll do things for me if I need anything' Support increases feelings of independence</p> <p>Support threatens feelings of independence</p> <p>'If anything goes wrong ...she'll put you in a home': Problems as formal support threatens feelings of independence</p> <p>'She does fuss': Problems as informal support threatens feelings of independence</p>
Living with Support	<p>'He's who I call in emergencies: Support in a crisis</p> <p>They're popping in and out all day': Feelings of independence maintained through responsive family support</p> <p>'It doesn't seem right': Feelings of dependence</p> <p>'Rubbing along': Reduced ability to maintain independence</p>

Matters of Concern	
Identifying concerns	<p>'They might not worry about it but I do': Concerns not addressed during the preparation for home</p> <p>Concerns about immediate practical arrangements</p> <p>Concerns about medication</p> <p>Concerns about not managing once home</p> <p>Financial concerns: paying for the home help</p>
Identifying Concerns while Getting Home	<p>'I'm not really anxious I'm just eager': No concerns expressed</p> <p>'That's a worry you know': Concerns not discussed</p> <p>'They're both very busy really': Relying on family</p> <p>'You feel a bit shaky': Concerns about falling</p> <p>'I didn't think of it before': Concerns not considered</p>
Concerns at home	<p>'I would probably talk to her': Concerns discussed with family</p> <p>On-going Concerns</p> <p>'Being a burden': Depending on informal support</p> <p>Living with Pain</p> <p>Living with Grief</p> <p>'What else is there?' Problems discussing concerns</p>

Managing Change	
Managing change with the help of others	<p>Support response as inclusive in the first week</p> <p>Changes in support after eight weeks experienced as appropriate</p>
Allowing others to manage change on your behalf	<p>Support response managed by family in the first week</p> <p>Changes in needs met through informal support</p>
Managing change made difficult by the actions of others	<p>Problems with support response in the first week</p> <p>Support Response experienced as problematic after eight weeks</p>
Unable to manage change	<p>An 'Unsuccessful Discharge'</p> <p>Disrupted Support</p>

Table 4.1 Showing experiences codes and emerging subcategories at the stage where dimensions are identified.

This process of organising and reorganising is on-going, reflecting the use of constant comparison. Table 4.2 is presented at the end of the chapter (see Section 4.5 Matters Arising) to illustrate which experience codes have merged and which subcategories have emerged as categories become increasingly developed and dimensions are more fully identified.

4.1 Making Decisions

A central category that emerges using a constant comparative approach to the analysis and collection of data is Making Decisions. Below, the experience categories that were collected under this category are evidenced. In the discussion section, the dimensions ‘voicing needs’ and ‘role in decision-making’ are suggested in response to the analysis of empirical data. These dimensions will be further developed in Chapter Five.

4.1.1 Experiences of Making Decisions

Experiences of decision-making during the discharge process varied across the group and the interview series. The experience codes are laid out in three stages: planning, enacting and reviewing. Collopy (1988) defines two aspects of decisions-making, decisional and executional autonomy; the first refers to the ability to make decisions and the second to the ability to have decisions carried out. This analysis allows us to explore the relationship between planning the return home, the period of transition and the period once home, where decisional and executional aspects of decision-making can be investigated and reflected upon.

4.1.1.1 Planning

Seven experience codes within ‘planning’ emerged from the data during analysis (see Table 4.1 above). *If I do have any trouble* reflects an experience of active decision-making where an older person talks about organising her own arrangements, calling on paid-for support to manage certain issues at the time of her discharge. *We’ve decided I*

might need help represents a situation of supported decision-making where informal support is called upon as a resource to provide help in making decisions about discharge planning; *my children will see to me* expresses a situation where an older person preferred that their view point be negotiated by a family member on their behalf. One of these participants also expressed an attitude to receiving help in decision-making from the medical team in *that's what you have doctors for*.

There were problems that arose during discharge planning. The emerging sub-category *planning made difficult by the role of others* includes two experience codes: 'he's coming... I don't know when', which reflects communication problems with doctors in relation to the date of discharge; and 'as far as she's concerned' where one participant talked about the problems that arose when trying to liaise with the warden while planning her return home.

Others expressed *feelings of exclusion from decision-making*; by the medical team in 'he didn't tell me' and altogether in 'no one really asked me'. Finally '*why should I?*' reflects a situation where an older person was not included in risk decisions in relation to her return home/ discharge date and her outright disagreement with medical opinion is not discussed with her.

'If I do have any trouble': Active in Decision-making

Mrs Heathfield was active in the decision-making during planning her return home.

Although Mrs Heathfield's family were not involved in organising her return home, she was able to 'buy in' support, and paid her friend Peggy to provide what help she may need. Mrs Heathfield, to a large extent, co-ordinated her own support provision, and felt

able to continue this active role in the planning of her care. She recognised the importance of having people to turn to if she needed help with this:

... You have to get back and then see if there's anything else that needs organising or whatever.

... If I do have any trouble I know there's people I can ask... I don't know where I'd be if I didn't have that.

Mrs Heathfield's proactive role was supported by hospital staff as they liaised with Peggy and the warden:

The nurse said she'd phone the warden and Peggy and so I'll ask her to get things ready. It's much as I left it I should think. I do have food in the freezer so I'm not worried on that score.

'We've decided I might need help': Family supports decision-making

This code reflects feelings of inclusion in the decision-making process. The title is a quotation from Mrs Manning who indeed expressed feelings of 'being involved' in preparing for home. She attended, along with her son, the family conference that began her home care planning. As a family, they were not dependent on means-tested social care, and were able to buy in the care as needed which was co-ordinated and paid for by Mrs Manning's family.

Similarly, Mrs Hodges felt supported, in part by her family; although they were not living close enough to be involved in her support on a daily basis. She felt able to manage herself as she had done before she was admitted to hospital. She felt included in planning

the return home: “We just got it all organised”; and experienced the arrangements to increase her home-help visits as appropriate to meet her needs:

I did feel glad of the extra help when I first got home. My daughter arranged that and the frozen meals, but I’m glad of it, she thought it would be a good idea and I agreed with her.

They both found the communication and co-ordination surrounding the day of discharge inclusive, effective and responsive to their views. Mrs Selby talked about her experience of organising her discharge:

They like to make sure everything is in order before they send you home and they like to make sure they do everything they possibly can...

She felt included in the preparations for the discharge as she was consulted about her arrangements at home:

I had a nurse ask me and we told her how it was here... and they asked if we wanted a home help... but I said we don’t need one for now.

‘My children will see to me’: Planning managed by family

This group of experiences show how some older people allow others to represent their point of view in decision-making and planning the return home. Mrs Woodward described how she felt included and her view considered:

They asked me how I would manage with everyday things, like walking and washing and dressing...they don’t send you home without checking there’s someone there to see to you for those things...but it’s already organised really.

Mrs Woodward also felt comfortable with allowing her family to make appropriate arrangements, and felt able to communicate any further problems to them:

Well my children will see to me... so if I've got a problem I'll ask them and they can see to it.

Mrs Westerby was unsure of any changes to her home arrangements as this was discussed between her family and hospital staff, however, Mrs Westerby was happy for her family to take this role and felt her daughter was responding to changing care needs:

I think we're getting a second help in. I was in in... erDecember....when I come in here... then I went out in the January.....and then I had to come back in again and I went in Ward [X] ...and I was in there about a week I think.... I come out and it started again.....so... er.... my daughter said she was going to make different arrangements.

Mr James described a similar situation, where he felt supported by his family and comfortable with them organising arrangements for his return home:

There's not much to organise really, just my tablets and Robert [son] will do those. He'll let the warden know what's happening.

Mrs Selby felt that she could allow the responsibility to pass to her relatives:

My daughter will sort it out.

This referral of responsibility for arrangements to her daughter reflected a trust in the latter to speak on her behalf. She did this as she felt her daughter would manage the situation with her best interests at heart:

Well, it is up to her. She's the one who knows what she can manage and what she needs help with.

In this situation, family advocacy was provided by Mrs Selby's daughter, who represented her mother's interests in negotiations with health and social care professionals in the planning of her discharge and support once home.

'That's what you have doctors for': Use of formal support

This experience code reflects the view that it is the doctor's job to make decisions about the definition of care needs and necessary support provision. Mr James felt that it was not possible to be in complete control of the situation:

You don't really know what to expect when you go home. I haven't fallen before and now I am worried that it will happen again. It wasn't like that last time I went home so I look to them [professionals] for guidance.

It's what you want nurses and doctors for isn't it. I'm not in a position to tell them their jobs.

When I was getting ready to come home I let them make the decisions, because it's like they said, they know what help there is out there don't they. I don't know what they can do to help me, but they do.

Mr James felt it was important to be guided by both professional and family advice.

Planning made difficult by the actions of others

This emerging sub-category represents experiences of older people who faced problems during planning and is made up of two codes: 'he's coming... I don't know when', which describes problems with formal professional staff and 'as far as she's concerned' which reflects problems with semi-professional staff.

'He's coming... I don't know when': Problems with Formal Professional staff

Three participants found the information given by doctors confusing and this made organising the return home more complicated. Mrs Hodges experienced little support from the hospital staff but initially did not see this as a problem:

Clare: So no one has been to talk to you about getting everything sorted out at home for when you are ready?

Mrs Hodges: Well no, but I think I'll just manage as I usually do...

However, communication about the date for her return home was confused:

Well, I don't know when I'm going to be able to go back to my own place... they haven't said anything... I was hoping they were going to say to me today that I could go but they never said anything about it... you know.. they looked at my papers and then moved off to the next person... so I couldn't tell you...but if I went home now it would be lovely.

Mrs Hodges was discharged with little prior notice but she felt supported and included in the process by her family:

Mrs Hodges: [The doctor] said to me one afternoon 'Would you like to go home Mrs Hodges' and I said 'Oh yes please' [both laugh] and he smiled. The next day I was hopeful but he just passed me by

Clare: Nothing else was said?

Mrs Hodges: Nope... not that day... not the next day...after a couple of mornings Dr M came and I don't think... no he didn't say to me you can go home.. I don't think he even spoke to me that morning... and the staff came and told me you see... it was a peculiar feeling... whether it's... normal to do it that way or not, letting you know the morning you're going... so, anyway, so... We [her and her family] just got it all organised...

Although Mrs Weeks was initially consulted about organising her return home:

The doctors came round today you know and they were saying that I could go home if there was someone about to give me a hand with things... but I think I can manage all right dear... I have been managing by myself for a long time now... and I do have Mark to help.../. He's who I call in emergencies.

However, she felt uninvolved in the planning of her support:

Mark [step son/carer] has a sick wife and he has to do everything for her... he couldn't manage both of us I don't think... so he asked them at the hospital for help with things... he'd be able to tell you the arrangements.

Communication between her and hospital staff, about which day she was to return home, was felt inadequate by Mrs Weeks as no explanation was given to her about why she had to stay over the weekend:

They did say Monday but I wanted to go home tomorrow [Friday]. The nurse, I asked the nurse and she said that Monday would be better and give me the weekend to relax... but I think being at home would be more relaxing for me.

Mrs Manning also found communication with medical staff unclear including the timing of going home:

Mrs Manning: He's [the consultant] the one that can say yes or no...and he's not come today.....normally he comes.....last time I saw him was the morning after I came in

Clare: Was that last week?

Mrs Manning Yes that's right...but he will be coming... I don't know when....you see I'm not used to the routine of the hospital you see I'm not used to it...but it seems silly to have me in here till Monday.

This led to frustration for Mrs Manning as she felt her plans for a smooth return home had been disrupted:

Mrs Manning It's so frustrating being stuck in here from Thursday to Monday [sighs] still if I have to do I will...there's no point worrying about it

Clare: It'll all be there to go back to won't it?

Mrs Manning Yes, yes it will.....yes but they'll [family] have started back to work... so it won't be so easy... I wanted to be in this weekend....and make plans if I could've gone today.

'As far as she's concerned': Problems with Formal semi-Professional staff

This experience code expresses the difficulties that can arise when a relationship with a carer is problematic. Mrs Branson initially explained that her family were organising her return home:

Clare: You're getting ready to go home. Is there anything the nurses have done or organised for you?

Mrs Branson: No it's all been done privately...my family have done it.

However, hospital staff did give some support in terms of communicating with those at home about restarting domiciliary support services:

[Staff nurse] said when you go will your cleaner be there? So I said phone the warden, tell her I'm coming back home.

Mrs Branson and her family faced an uncooperative warden, who was less than helpful following the loss of Mrs Branson's keys (see Section 4.1.1.3 Reviewing: *overstepping the mark*):

... and she has never once let on to my daughter or told my daughter anything about it...[Pause]...as far as she's [warden] concerned I've got no keys.

This action by the warden made planning and organising Mrs Branson's return home more complicated than necessary, restricting the effectiveness of Mrs Branson's decision-making and in turn her access to executional autonomy (Collopy 1988); that is, the warden's actions made it more difficult for Mrs Branson and her family to carry out the discharge plan as they had decided.

Feelings of exclusion from decision-making

This emerging subcategory includes two experience codes: 'he didn't tell me', which reflects the experience of being excluded from planning the return home by the actions of doctors and 'no one really asked me', which reflects feelings of exclusion from taking part in planning in a more general sense.

'He didn't tell me': excluded by doctors

Mrs Trent did not feel included by the doctor or consulted in relation to her arrangements for going home:

I never have any help now... I do it all myself you see...since I've been in the hospital they said I shouldn't be doing you see...though he didn't tell me...he wanted a word with my daughter and my son in law...he got them talking and he told my daughter he said when I come home 'She's going to send me a home help'.

... So what they're doing now, they rang me daughter up, is sending me a home help in.

She also felt her family should have consulted her more closely starting the home-help service, especially as she had to pay towards it out of her pension:

Well, I have enjoyed the extra help; I must say that's true. I didn't mind really, I have always managed for myself, right up until I went in, but they could see I needed something and they were right as it turns out, that's true. But the doctor talked to them about it, and you would have thought they'd have said something to me as I'm paying out my pension, but what you can't do for yourself, and what your family can't manage, well, someone has to help you really don't they?

'No one really asked me': Non-inclusive Decision-making

Mr Charles' lack of participation in the planning of support for the second discharge reduced his feelings of control over his situation:

No one really asked me what I thought about going home. They assumed a lot, but they didn't ask me.

He did not see requesting certain help, or for support to be provided in a particular way, from a particular source, as part of his 'responsibility', but instead associated asking for help to be provided as 'greedy' and inappropriate:

I'm grateful for whatever help I can get. It's not up to me to start demanding help for this or that. They do what they can and I have to manage what they can't do.

It isn't set up to give you what care you think you might need. I'd like a swimming pool but I don't think they'd build me one if I asked them do you?!

Lack of control and autonomy, the feeling of there being 'no point' in asking or requesting help in decision-making was apparent amongst some of the older people in this project, who felt that they should be grateful for whatever help they could get, and saw problems which were not supported and needs which were not met by the professionals, as something they had to manage or get used to. Needing more help than was immediately forthcoming was associated with personal responsibility, notions of greed or 'being spoilt' and being more dependent than was appropriate.

'Why should I?' Disagreeing with Doctors

Mrs Andrews was admitted with an exacerbation of asthma, but once admitted the hospital team were concerned that she was not 'managing' at home and that she was at risk from falls. She remained in hospital after her initial problem had been addressed to allow time to consider these issues. However, she did not realise this, and therefore did not agree with the management of her case by the hospital staff.

Mrs Andrews did not agree with what the doctor said about the timing of going home:

Mrs Andrews: The doctors came... he said to me, he said: 'If I let you go home you'll be back in again won't you'... Why? He said 'I can't stop it'. I've got asthma love, so he says to me 'I can't stop you getting short of breath', but of course they can't 'cos they can't cure it can they?

Mrs Andrews: 'Oh no' he says, 'I can't let you go, you'll just be back in again'. But I think it's ridiculous don't you? Hell I'd be better at home, you got your own surroundings.

Furthermore, she picked up a hospital-acquired infection, but was not provided with appropriate information, either with reference to the fact that the infection was on the ward, and therefore a risk, or what the symptoms were, or that her experiences of diarrhoea were due to this infection. She was therefore not in a position to make an informed choice to remain in hospital, and her decision to leave, expressed in terms of complaints at staying and a desire to return home, was not addressed by staff:

Mrs Andrews: I picked up diarrhoea in here... I was really bad with it, it was running from me. It [*Clostridium difficile*] was on here a fortnight ago. It turned to blood love, I thought I was having my periods... God.

Clare: How long did that go on for?

Mrs Andrews: About a fortnight, two weeks.

Clare: You must have been exhausted.

Mrs Andrews: And I was shouting for help... they ignored me... I did it in the floor they had to come and clean it up... (sighs) Well it weren't fair was it lovey?

Mrs Andrews: So I just said to her [nurse]... why have I got diahorrea? I never came in with it. I didn't know nowt about it. She said 'Oh now there's a few of you that picked it up'. I didn't know nowt about it. I know I got it alright. I was amazed when I found out...

Clare: That you could catch stuff in the hospital?

Mrs Andrews: Yes, that you caught it and I caught that... Ohh I say love. I was getting wind up what with loosing blood and all, wouldn't you?

Clare: And of course you'd be losing weight as well.

Mrs Andrews: Oh yes... I thought to myself, I'm getting worse not better I'm getting out of here (laughs).

Clare: So they've not actually given you a date.

Mrs Andrews: No I hope he'll tell us today when he comes... that's what he said to me... 'If I let you out you'll be back in again'. Why should I? Why should I be back in again?

Mrs Andrews had good reason to feel concerned about her safety in hospital, even though she may have problems caused by possible falls, or exacerbation of her asthma (for which she was admitted), but she felt these potential dangers were not as threatening as the possibility of facing a worsening in her condition from catching hospital-acquired infections. The doctor did not address her concerns. A second point raised by Mrs Andrews' experience is the lack of information being given to older people not only on preparation for discharge, but also in terms of the possible dangers and decisions regarding risk while in hospital. Mrs Andrews was not given the appropriate information. She was not made aware of the dangers of a hospital-acquired infection known, to be on

the ward, nor how to reduce the personal risk of catching it. This also represents a lost opportunity to support Mrs Andrews and facilitate her own risk decisions.

4.1.1.2 Enacting

There are three experience codes that emerge as sub-categories within 'enacting'. *I think I can manage* represents an experience of active participation in the movement from hospital to home; *my daughter brought me back* represents the experience of this transition managed by the family; *they remembered me when they got to the end and there was a meal left* expresses an experience of this move home as problematic.

'I think I can manage': Active participation in transition

Mrs Hodges felt positive about going home:

Mrs Hodges: I'm looking forward to getting back to my own bed... and well...it's not very interesting in here

Clare: Do you walk up the ward to the day room?

Mrs Hodges: No I don't go up there...you can't choose what you're going to watch [on TV] anyway.

She highlighted the need for an adaptive approach:

The thing is I feel well enough to manage and I want to get back into the stride of it... otherwise you lose your nerve you know, you have to get on with it and see how it goes, don't you?

Mrs Hodges found the ambulance men helpful to a smooth transition home:

They were very nice the ambulance that brought me home... I could climb up the steps to get in and they were going to help me and I said 'I think I can manage', which I did but when it came to getting out I looked and thought 'Oh no'... and said 'Can I have a hand please'.

They were very good. They carried everything in for me.

She received support from her family, especially her daughter, in the transition from hospital to home; her son was also there on her return, although he did not stay more than an hour:

Jane was here of course, oh it was John 'cos he'd been getting locks organised.

Mrs Heathfield was positive about going home:

I am looking forward to going home... to get back to my own bed and have some sleep.

Paid-for support (Peggy) smoothed the transition from hospital to home. Peggy picked Mrs Heathfield up from hospital and settled her in at home:

She [Peggy] came and picked me up and brought me home ander... I sat down and she made me a cup of tea...and that was that...

I can't remember what I had for me tea [laughs], it was something I had that I had... 'cos I've to have all these ready meals....amazingly I slept right through...I was quite alright ...yep...I've really settled in really well this time.

Although she was pleased to get home there were things about hospital that she missed:

I was very glad to get home...get my own bathroom ...but yes I did miss it
[hospital]....found everything very quiet when I got home.

Mrs Andrews did not feel that she needed extra support during her first twenty four hours home:

All you want to know is, is someone going to take you home and 'chuck you' in if you want and clear off at least I do anyway.

However, she did receive some supported from her brother in her transition from hospital to home as he was there to meet her when she arrived and had ensured she had food.

Mrs Weeks looked forward to going home, although once home also missed the reassurance of the hospital:

I'm looking forward to a bit of peace and quiet and to be honest a bit of privacy.

Mrs Weeks: It's nice to be back in my own little place... although it is a bit quiet.

You get used to all the flurry and activity when you're in hospital

Clare: Do you miss being in hospital?

Mrs Weeks: No, not really dear, although it is quite reassuring.

She returned home by hospital transport and received no direct support from her stepson with the transition from hospital or within the first twenty four hours after returning home:

I'd rather get myself back into the swing of things before I have to deal with him.

‘My daughter brought me back’: Transition managed by family

Some individuals did not take an active role but let their family manage the transition home and speak on their behalf. Mrs Trent remembered little about getting home, although she was picked up and settled in by her daughter. Mr James found his discharge supportive due to the help he received from Robert, his son, who brought him home and settled him in and ensured there was food for the evening. Mrs Selby, supported by her husband and children, found returning home unsettling:

Well it’s been a bit of a whirl since I come home. We haven’t got organised yet... but it will come.

My daughters been here...she’s taken time off work and spent most days here... we’re nearly settled.

Mrs Westerby was pleased at the possibility of going home:

[I’m] not really anxious I’m just eager... to make myself more comfortable. I’ve just had a new carpet and everything...I paid £395 for the carpet...and they said you just sink in it which I like, and a glass top table which I always wanted... and a new television....so what more can I ask for?

She felt supported by her family in the transition between hospital and home:

My daughter brought me back, and they were all here when I got in. It was lovely to be back.

Mrs Manning was pleased to be home but missed the support she had in hospital:

It was lovely to get home...back to my own routine and see the family you know.

It does seem really quiet after the hospital you know... there [in hospital] there is always someone to talk to or if you're in difficulty there are people who can help you... whereas here if there was to be an emergency I would have to wait until they got here wouldn't I?

Her transition home was smoothed by the support she received from her daughter:

My daughter came to see me on the evening and she'd got everything ready... some food and aired it through so she got it ready for me to come back to.

Mrs Woodward experienced no problems on transition from hospital to home. She was picked up by her daughter and settled in at home:

Paula [daughter] is coming to the test with me on Monday and she'll be able to give me a lift and get me settled.

'They remembered me when they got to the end and there was a meal left': Problems with transition

Mrs Branson's experience of the transition home from hospital was complicated by the pressure on beds and waiting for hospital transport:

... I was glad to get out...they came to me... the male nurse... and said 'Would I mind waiting in the day room'...'cos they needed the bed. So I said 'No of course'. So they bundled me into the day room at eleven and I didn't go home while five in the evening...they remembered me when they got to the end and there was a meal left over.

4.1.1.3 Reviewing

Reviewing contains five experience codes (which emerge as sub-categories) evident once older people had been back at home for eight weeks. Three express different types of inclusive decision-making; the first reflects a situation where an individual takes a lead in decision-making and manages her own support; the second discusses a situation where an older person took an active role in decision-making about one aspect of the support she received once home, despite perceived potential problems; the third examples a dynamic where an older person is given some help in the management of her support by her family.

Two sub-categories represent barriers to decision-making once home. The fourth emerging sub-category discusses a situation where an older person has to adapt the support she has access to as it does not meet her understanding of her needs once home. The fifth sub-category expresses feelings of reduced control as decision-making is limited by the actions of formal support.

‘Peggy helps me’: Leading the decision-making

Mrs Heathfield was able to ‘buy in’ support provision to meet her care needs. Her relatively high level of economic capital allowed her some autonomy in her decision-making. She had help with housework and shopping provided for her by Peggy, who ensured Mrs Heathfield had what she needed to manage.

She’s very good, she’s really very good, and of course without her I wouldn’t be able to stay here like I do. It’s important that she is someone I know, it wouldn’t be the same if you have a stranger to look out for you, I wouldn’t be able to do things the way that I’m used to. But Peggy knows what I like, and although she is very busy, she does do a lot for me. Of course I don’t know what it would be like to not have that choice, but my family live, well they are away from here, and although I

do see them they aren't close to hand, so Peggy's like that, and does what my family would do if they could.

Mrs Heathfield had bought the adapted flat she lived in within the sheltered flat complex, and had also liaised with a number of agencies (such as the local Institute for the Blind) to arrange for the instrumental support she needed, such as a magnifying glass for the television and the large button, amplified phone.

'I'm not having that': Active in decision-making

Mrs Andrews discussed her active management of the support she had available to her when she talked about her experiences with home helps, initially as she prepared for home:

Clare: Doesn't anyone come in to help?

Mrs Andrews: Oh I did do... I chucked her out

Clare: Did you?

Mrs Andrews: Oh yes I did ... I'm not paying for that for nowt... well she went into the bathroom, well I was disgusted (pause) well it's alright love but your bathroom mat is really just talcum powder and all like that... she picked them all and shook them all in my bathroom, she didn't take them outside... She should've sat them to clear. When you've been doing for yourself you've got your own standards.

On getting home, Mrs Andrews found that the bought-in-help that had been organised was not suitable for her:

Clare: So have you got someone who comes in to help with the housework and things?

Mrs Andrews: Well I have got one, but I'm getting rid of her. She's rude, comes bursting in without a proper hello and she hardly says a word, swans about like she owns the place and leaves. I'm not having that, and I'm paying her, she's not doing me a favour.

Eight weeks after her return home, Mrs Andrews experienced mixed success with her proactive attempts to find the support she felt suited her needs:

Clare: Do you have a home help?

Mrs Andrews: Well, there's a thing. I have had home *helps* [laughs]. It's not me, I don't mind having help, they said that but it's not that, I just didn't like them. I'm not paying to have someone in my house who I don't want, but they think I'm in it for the trouble. Well I've had two since I came home. That first one, I asked her to leave, and they said I should think about moving to a home where they could do it all for me. I wasn't hearing of that, I'm not going to rot away. But then I got [Tanya] and we've got on really well. She said she thought I was going to be trouble but didn't know what the fuss is about. So that was alright. She's thorough and sits for a cup you know. But yesterday she told me she was stopping. You get one trained up in the way you like things, and then the next day it's a complete stranger and you have to start again.

Although Mrs Andrews felt constrained in some ways by the support available to her, both in terms of the particular home helps, but also in relation to support for her decision-making, she maintained some control over her situation by making and enacting certain decisions, despite the danger of being labelled a 'trouble-maker'.

‘We’re managing fine’: Decision-making supported by family

Mr James managed his daily personal care with the support of his son, Robert, who visited to help his father up in the morning and to help him to bed in the evening. Mr James felt he was able to maintain privacy at a level that felt comfortable to him, as he was happy for his son to provide personal care. He was able to manage bathing in his adapted home, but preferred his son to be there as reassurance, to help:

If I slip or whatever, I’d rather have him there, so he can sort it out. It means that if I go steady I can do for myself.

Robert was involved in his father’s care with regards to ensuring the housework was done and to act as ‘back up’; to provide Mr James with an atmosphere that gave him the confidence to manage his own personal care.

Mrs Selby received personal care from her husband pre-admission, this continued while she was in hospital, as he arrived early every day to help her with her morning wash. Mr Selby was supported in this by their children, mostly their oldest daughter, who felt that her father could not cope without their support. Mrs Selby was able to rely on those she trusted and who were close. She was able to turn to her husband for help in the maintenance of her privacy whilst receiving support to meet her personal care needs.

‘They say I’m not supposed to’: Adapting available support

Mrs Weeks felt able to define her own care needs. However, she was not always successful in having her opinions heard and was not always consulted. She did not have the opportunity to discuss the problems that arose with regards to appropriate pain control (see Section 4.2), but managed the balance between relieving pain and feeling too sleepy herself.

Inadequate consultation had also led to adaptations to her home being ineffective, in particular the rails round her bath, which were provided with a view to making the bath appropriate to her needs but which she could not use due to a lack of strength in one arm..

This was also apparent in the provision of a trolley that did not fit round her furniture; again she adapted her behaviour to make the most of the support available:

Well it's one thing in hospital but once you're at home they don't know what you're doing. I had my home help move the front room around so I can get about by leaning on the furniture and I don't have to use that trolley they gave me in hospital. It just doesn't fit round my furniture, so I thought it'd be safer to do it this way.

I'm supposed to take it easy, not walk about too much on my own, but I think, they don't have to live like that and I don't want to, so when everyone has gone, I get up and move about like this [moves from table to sofa, holding on to furniture] they say I'm not supposed to but there's no one here to tell me.

'Over stepping the mark': Limited by the actions of formal support

Mrs Branson expressed feelings of reduced personal autonomy when she talked about an assessment made by the district nurse in her own home:

I've had a nurse on Monday and a lady to see me from the hospital yesterday and one of the questions she asked me yesterday was 'Was I incontinent?'...and that did annoy me... and I said 'I can still go to the toilet and I can still wee and I can still pooh' [both laugh]. I don't do it in my knickers you know... but because I'm

80 people seem to think...people are just assuming that I've lost some of my marbles.. that they've gone missing somewhere [laughs].

This parallels the concept of intrusion on informational privacy (Michael 1994, Schopp *et al.* 2003, Scott *et al.* 2003b, Woogara 2005); Mrs Branson was asked for more information than she felt necessary about a topic she found insulting and represented feelings of reduced control over decision-making in relation to choosing what information is discussed.

Mrs Branson lived in a warden-supported flat; however, she did not have a good relationship with the warden, who she felt was patronising and something of a bully to the older people in her complex. She was concerned that the warden was able to influence professional opinions more than she could, and felt that she was living under the threat that she may be classified as 'in need of residential support' as Mrs Branson was frightened that the warden of her sheltered housing could 'get her put in a home'. Mrs Branson felt the professionals were in control of what happened to her and her own opinion could be easily over-ridden. This was emphasised by the attitude of the warden. Mrs Branson felt the warden did not 'care' about the older people who live in the sheltered flats:

Mrs Branson: I've been in here a month and she's been in here once to see me

Clare: Is it a bit of a difficult relationship with her then?

Mrs Branson: Yes... that's it, she's been to see me once.

This 'difficulty' with the warden was also experienced by other older people. Mrs Branson talked about one resident she felt was in a worse situation than she was:

One of my neighbours fell, she fell doing a favour for somebody. She fell down three stairs and broke her ankle. She come into the hospital and she had plasters put on and whatever, the warden never went to see her once in three weeks.

Mrs Branson reported how others involved in the support of older people within the complex were also concerned:

Mrs Branson: Some of the [board of governors for the sheltered accommodation] don't like her either. She's got a bad name for herself

Clare: So you don't get on with the warden very well

Mrs Branson: No, nobody has a good word for her.

The problem was not 'all wardens'. Mrs Branson had got on with at least two other wardens in the past. The current warden compared poorly to other wardens Mrs Branson had known:

I've lived there fourteen to fifteen years but she's only been there about three or four. The one before that was a gem, she sits on our council now. And the other one was married, and on a night time you know if anyone was disturbed, you could see her with her coat over her nighty and him with a coat over his 'jamas having a walk around the block you know to see if they could see anything.

The current warden appeared to Mrs Branson as more interested in her own private life and money, than caring about older people:

This one [the warden] parted with her husband, divorced and give him the old heave ho and now she's got a toy boy, but her mind's not on the job is it?

The warden seemed to Mrs Branson to be using her position to take advantage of the older people and their need for help, stating: “She got the job for easy picking” and gave an example of this:

I need a cleaner since I lost my sight and she said ‘Oh I can get you a cleaner’, and guess who her cleaner is? Her daughter and her daughter’s got a girl aged 13 and boy aged 9 and she’s just had a baby. She comes once a week for an hour and she charges £5 for the cleaning and £5 for the ironing, that’s £10 for an hour’s work and she goes to 3 other people, all in the same block and some of them she’s only there half an hour... and she charges them £5 so whose laughing?

Mrs Branson felt the warden showed the older people little respect:

One of the problems one of the residents has is that she talks to us as if we’re children, er, you know we have a centre where you can take part in things which have all been stopped. All the activities have been stopped.

If she has a complaint she’ll come in the doorway and she’ll say ‘You did so and so and so and so’ [imitates parental voice and wags finger] and everybody gets told off like that.

This included ‘telling them off in public’ unless the individual acted to stop this: They have noticed that the only time that she tells you off privately is if you put the door to, shut the office door so she can’t make a public show of it.

The warden also talked to their relatives as if they were children:

My eldest daughter said ‘She spoke to me as if I was some snotty-nosed kid’.

Mrs Branson's keys were lost, misplaced by the ambulance men and despite her daughter's attempts to retrieve them from the laundry-room, Mrs Branson was without keys to the building, as well as her own flat. She described the lack of help she received from the warden, towards finding or replacing the keys and therefore making Mrs Branson's return home more stressful for her and her family:

Mrs Branson: The ambulance man said he'd put the keys in his pocket but they lost them in the meantime. So my family couldn't get in 'cos nobody had a key and they had to keep going to the warden and then when she came to see me the first thing she said, she walked in and said 'Your daughters' have lost your keys you know that don't you?' My daughter never went there, she came straight here; she never went to my flat

Clare: So the warden didn't give you the chance to explain what happened?

Mrs Branson: No and my daughter has gone to the person that answered the button, spoke to him and he referred her to the ambulance man. She got the name of the ambulance man that came. He remembers locking my door, he thinks that... er... it got mixed up with the dirty washing, the blanket. She's contacted the laundry, but there's no way they can find them in the laundry, and the laundry did say to her: 'Don't worry. If it's a bunch of keys, no credit card or anything, then nobody can use them'. So I personally have paid to have more keys cut... and she has never once let on to my daughter or told my daughter anything about it.

[Pause]

Mrs Branson: As far as she's concerned I've got no keys.

Mrs Branson: My son-in-law went, he said 'Could I have some keys, the duplicate keys?' So she went something or other about, you know, she wanted them back. So he said 'All I want is to get into my mother-in-law's flat. I'll bring

them back as soon as I've done what I have to do'. He wanted some clothes for me you see So anyway, in the meantime they had a spare key on my original ring, so he took that, which covers the front door and the back door of the flat but for the outer front door and outer back door he borrowed the lady next door's.

So he borrowed her keys and had a key cut for her and a key cut for me and a key cut for them So I've got a key for the front door and a key for the back door. The only thing I haven't got is a key for the letter box.

But my daughter said 'If I catch her opening your letter box she's in trouble'... Everybody's aware; a lot of people refer to her as 'she'.

Mrs Branson was aware of the effects of the warden's attempts to disempower her, or at best, the warden's lack of support in maintaining Mrs Branson's dignity and respecting her autonomy.

The only thing is with this warden. I have a horrible feeling that if anything goes wrong 'out' [gestures with thumb over shoulder] you know, she'll put you in a home.

4.1.2 Discussion

Two central dimensions emerge from the analysis: voicing needs and role in decision-making. Each will be discussed in relation to theory and research, policy and law and finally practice in more detail in Chapter Five (see Section 5.1.1).

Many older people in this study experienced decision-making supported by formal carers, however a number reported experiences where autonomy was restricted by the actions of formal and informal care workers which left them feeling they were not in control of their return from hospital to home. Although policies impact on the individual's day-to-day experience, it is the type of relationship built between those providing the support in day-to-day living and the individual who experiences care needs that can impact directly on an older person's agency in taking part in decision-making. The latter must feel valued and their point of view is being listened to, in order to take advantage of the enabling policies that are in place.

A number of issues arise here. Different individuals discuss different experiences but they are all involved in power dynamics and 'achieve' care through the social relations of care. These are socially and culturally constructed as 'actors' interact in the context of care that is patterned by differences between the statuses of those involved. 'Capital' (Bourdieu 1986) is a useful concept in relation to this debate; those with access to high levels of social capital, that is, strong and appropriate family support (Wenger 1997), were able to access informal advocacy through family action; those with access to economic capital were able to access the necessary support to maintain a good quality of life.

It is essential for effective decision-making to have access to information and advice; however, advocacy and counselling are also necessary to support older people as they identify their needs and define their own understandings of 'quality of life'. Professionals have a role to play in the provision of this support either directly or through referral to specialists. Directly, they must provide an appropriate and supportive environment through their relationships with those in their care, in order that older people can

participate in the planning of support. This requires advocacy skills and an understanding of how the older person views their care issues, so that proposed support options respond to an individual's life aims (Tanner 2007). These skills can be seen to be included in the training of professionals, such as doctors, social workers, nurses, who assess and care plan for older people returning home, however they are not so prominent amongst those who have not received professional training.

Advocacy in the 'moment of care' is not always accessible; that is, having a 'voice' in decision-making is reliant on the type of relationship that exists between the carer and the individual. The 'respectful relationship' that is conceptualised between professionals and the people they support is not necessarily the ethos of those providing the 'hands on' service. Being able to make autonomous decisions about daily care within an empowering and supportive environment is central to the notion of person-centred care, necessary in sustainable care planning (Tanner 2007) and crucial to building confidence amongst older people in their ability to make decisions and voice an opinion.

Two dimensions to the category Making Decisions were identified through a process of constant comparison, and asking questions such as: what links these experience codes and what differentiates them. In the light of research, policy and practice guidelines, the two emerging dimensions are 'voicing needs' and 'role in decision-making'.

Voicing needs: The importance of the individual's voice is apparent in policy and practice codes and research shows the importance of being able to voice an opinion. An older person must be able to voice their opinion about their care needs as they see them and how these needs are to be met. The majority of older people in the interview group

were able to have their opinion voiced, either by themselves or by others on their behalf. However some discussed experiences where the actions of others made voicing their opinion difficult and others who did not feel they had the opportunity to put forward their point of view. The dimension 'voicing needs' therefore is a continuum that includes the properties: 'being able to voice needs', 'negotiating voice', 'voicing needs made difficult' and 'not voicing needs'.

Role in decision-making: The second dimension that defines Making Decisions as a category is the role of the individual and/or the role of their view in the decision-making process. Voicing an opinion is one aspect of making decisions, having that view considered is as important (McCormack 2001). Research shows that the most effective decision-making dynamic is that of person-centred care, where an older person's view is central to decision-making. Therefore the dimension of 'role' includes properties: view as central, view included, view overruled and view excluded.

4.2 Feelings of Independence

A second central category that emerged from the data refers to Feelings of Independence in relation to experiences of returning home from hospital and receiving support. As members of a wider society in which old age is associated with increasing levels of dependency and within which ageist attitudes remain largely culturally dominant (Hockey and James 1997, 2003), older people themselves may hold views that see 'old age' as a period of growing dependency. For some, the experience of 'being old' refutes these ideas, for others the experience of 'being old' amplifies these opinions.

All of us, as social beings (Marx 1859) necessarily experience an interdependent relationship with others (Wilkin 1990). Emphases on maintenance of independence in policy and practice, and the cultural focus on the relationship between independence and 'full adulthood' (Hockey and James 1997, 2003), leads those who are visibly dependent to have low status, associated with the category 'child' (Hockey and James 1997, 2003). However, it is having the power to determine our own actions within our daily lives that defines 'independence' and which includes both the will to present ourselves as independent, and the ability. To require support is not necessarily a source of being defined, by both self and others, as dependent. For some in this group access to support fostered feelings of independence. Appropriate personnel and instrumental support provision helped older people to feel 'enabled' and increased levels of independence in their daily lives, for others issues of dependence were associated with accessing and using services. Experiences concerned with notions of independence changed across the discharge process; this category is therefore divided into three stages: coping in hospital, that refers to the balance of needs and support that exists before discharge (during 'preparing for home'); consuming support that refers to experiences during the move home and first week home (getting home) and living with support that reflects the balance of needs and support on 'being home'.

Two general types of support are considered: instrumental and personnel support.

Instrumental support includes enabling equipment and environment, for example, adapted and purpose-built homes; personnel support can be provided through formal or informal sources. Formal support includes both professional workers, such as nurses, doctors, general practitioners (GPs), community health practitioners including health visitors, occupational and physiotherapists and social workers, and semi-professional workers,

such as home-helps, care assistants and bought-in, private help. Support could also be provided by informal carers, family, neighbours and friends, as well as those in the social network that were not directly involved in physical and practical aspects of care, such as friends, associates and neighbours.

How receiving support is experienced reflects a balance of two central issues, namely, levels of access to an enabling environment and access to empowering support. An enabling environment refers to timely access to instrumental support that is appropriate to an individual's needs; empowering support refers to the actions of both formal (professional and semi-professional) and informal (family, friends, neighbours) support that is responsive to changing needs. The experience codes below show that different balances between these two strands can make the difference between feeling independent as a result of consuming support and feeling dependent because there is no choice except to consume the support made available.

4.2.1 Experiences of Independence

4.2.1.1 Coping in hospital

This stage, the preparation for home, contains two groups of experience codes that discuss growing *feelings of independence in hospital* and *feelings of restricted independence in hospital*.

Feelings of independence in hospital

This emerging sub-category contains three experience codes: 'I see people worse off than me', which reports older peoples' experiences of recognising their growing independence; 'now I do for myself', which reports the experience of rediscovering independence and 'he comes in to help me', which reflects the experience of family support in the maintenance of feelings of independence.

‘I see people worse off than me’: Recognising Independence

Some older people found being in hospital made them feel more independent in comparison with others. Mrs Selby described herself as ‘a little bit independent’ and tried to do what she could to help herself:

Well, I’m a little bit independent, I know I shouldn’t but I like to think well, I can do something for myself, ’cos when I look round I can see people worse off than myself; so I think what I can do myself I’ll do it you see.

Mrs Andrews talked about her improved ability to manage her own needs:

Well they moved me down here [to a shared cubicle at the end of the ward]....why? They said well you can look after yourself... I do all me own er... [indicates own inhalers on the table].

I do this myself here (self medication) I’m looking after myself...I can take myself to toilet and everything.

Mrs Andrews commented on the comparison between her abilities and the abilities of others as she saw it:

Well what annoyed me was love when they brought me into here they said ‘Well you can look after yourself’.

..... Why the hell can’t they look after themselves [indicating the other patients] in *their* own way.

Mrs Trent also felt more able than other patients on ward:

We pick the frames up ourselves and walk with them you see. Well I don't particularly need one but they do [other patients] I could do if I wanted to but I'm alright.

When you see them that can't do for themselves, it makes you feel glad with what you can do.

'Now I do for myself': Rediscovering independence

A number of older people experienced feeling more dependent on help from hospital staff as a result of illness, but were rediscovering their independence as their health improved.

Mr James described his progress during his stay:

To start with I was down there [nurses' station] and they had to do everything for me...but as I got better they moved me down here. I asked why, why do I have to move...and they said there's others iller than you ...so I came down here [in a bed away from the nurses' station] and now I do for myself...I was pleased really cos it meant I'm getting back to normal.

Mrs Hodges expressed her desire to get back to her everyday life:

I still don't know why I'm still here. The thing is I feel well enough to manage and I want to get back into the stride of it, otherwise, you lose your nerve you know... you have to get on with it and see how it goes don't you?

'He comes in to help me': Independence supported by family

Mrs Selby talked about how her husband came in to the hospital to help her with daily care needs such as her washing and dressing.

He comes in to help me, every morning and he's here for a lot of the day But he does get tired and my daughter comes to pick him up after dinner, so I sleep on the afternoon. He helps with my wash. He does at home; we've got our way of doing things there, but here it's just round the bed, you know.

We'll do as we usually have [once home].

'Using your own': Feelings of restricted independence in hospital

Mrs Hodges also felt that being in hospital made it difficult to maintain independence; she found that she was not able to use her usual independence strategies:

It's not always easy to sleep in here... there... well some of the people shout out in the night and you can doze off and then someone shouts out and you're awake again... and it's not as if you can wander about... or make a hot drink or put the television on or whatever... so it can be hard to get all the rest you need and I am tired.

Mrs Woodward talked about how being in hospital made it harder for her to manage her continence issues:

Mrs Woodward: Oh well I do have a bit of trouble now and then [occasional urinary incontinence] but I have had ten kids [laughs] but I have a toilet downstairs, it makes it easier, if I get caught...short.

Clare: Do you sometimes get caught short?

Mrs Woodward: Well it happens, you know, as you get older, you get used to ityou wear big knickers, Harvest festivals: 'all safely gathered in'. [both laugh]

Clare: Has anyone talked to you about it or offered any help with managing it?

Mrs Woodward: I wear pads and that helps, it's not so easy here...it's easy to get caught out ...the loos are over there [indicates half way up the ward] and I'm not so nippy. I've used a lot of their pads; but they've got a pile so I don't think they mind [laughs].

Mrs Branson felt that being in hospital made her less able to manage as she usually did:

I want to be free, of here...because I don't sleep very well and I'm used to getting up 'cos I've got a recliner chair and I'm used to getting up and sitting in my recliner chair and maybe having a little doze... getting up ... walking about and then getting back into bed again.. Here I can't do that. In fact they have a recliner chair but it's only for the very poorly.

Mr Charles found being in hospital limiting:

I don't want them all fussing. They do what they have to do, I need them or I wouldn't be here. But at home I can do the way I feel comfortable. I can't get to the toilet on my own here, and I have to wait for someone to help me out but at home you can go when you want. I wouldn't choose to go to the day room though I like to watch television of an evening but it's too far and I need help to get there and back, the nurses have enough to do.

Mrs Westerby felt less able to be 'independent' in hospital; at home she and her family had organised her home so that she was able to manage on a day-to-day basis; being in hospital disrupted the way she managed her condition as she was unable to sleep, watch television and get to the toilet as she needed.

The issue of maintaining independence was also discussed by Mrs Andrews:

Mrs Andrews: You can't go to the toilet without everyone knowing about it.

Mrs Andrews: [In hospital] everyone knows what you've been up to, they all know who has been to visit or whether you've had visitors or not.

Clare: It's quite a step from here as well isn't it (toilet is at the other end of the ward).

Mrs Andrews: Yes... oh yes that's the place I want to go home for to be honest.

Clare: Going to the loo?

Mrs Andrews: Oh yes lovey I mean they go... up to the toilet and they can't be bothered to flush it and you go in... oh god... turns you up dunnit... you must admit love... you wouldn't like it.

Mrs Andrews felt more independent at home:

Hell, I'd be better at home.....you got your own surroundings, I can get my own dinner.

Mrs Heathfield talked about the importance of being at home and having access to her own toilet and bathroom. Her son lived out of town and Mrs Heathfield relied on a paid helper, Peggy. Mrs Heathfield lived in a warden supported, purpose-built flat which had the necessary adaptations and equipment, provided privately by Mrs Heathfield herself. She talked about previous experiences of restricted independence, how, pre-admission, her privacy needs limited her ability to stay at her son's home:

I used to go [to stay with my son] quite a lot when I could go and stay with them.. but I like my own bedroom, my own bathroom...

What with the business of all the tablets I've got to take... it's not convenient in somebody else's house is it, and I'm on four water tablets a day, ever so heavy... ever so heavy.

Mrs Heathfield talked about her difficulties meeting her privacy needs relating to continence and personal hygiene in hospital. A combination of environmental restrictions (the layout of the ward), her own personal medical treatments (laxatives and diuretics), her level of mobility (using frame) and staff action led to difficulties in maintaining privacy in washing and dressing and the management of elimination (Roper *et al.* 1980):

I was a long way from the toilets yeah, and I was walking with that [points to betaframe]... the water tablets I managed quite alright but when I needed the laxatives that was... 'cos by the time you got the urge and I got down there...quite a few times I dirtied myself... which is distressing... I couldn't help it but I couldn't make [it]

... and then sometimes somebody's in the toilet and you can't get in... I didn't like that at all... so now it's sort of nice to be... 'cos I still have to take the laxatives.

Mrs Heathfield talked about managing her own personal care within the resource constraints apparent on the ward:

Mrs Heathfield: It was ever so dirty Very often they didn't pull the chain... sometimes it was on the floor... the seat was messed up... I mean they didn't clean it often enough... I know they're pushed for time.

Clare: It should be priority really.

Mrs Heathfield: We all think it should... and you didn't like going in... now that probably was a fault, it really was. But I know they work so hard and they're so

good, I wouldn't like to sort of blame them but the toilet really is appalling. I mean a lot of people are using it and most of them have had laxatives.

Clare: And a lot of them aren't exactly sprightly so...

Mrs Heathfield: No they're not, no there was very few walking you know... very few.

Clare: And it is amazing that you would have older people somewhere where they can't reach the toilet and then give them four water tablets and then laxatives and then they're right in the corner.

Mrs Heathfield: You hear them coming with the tablets you see... the laxatives yeah... 'how's the bowel... have you been today?' [laughs] laxatives oh [sighs] I mean I understand but er... it's a very big ward ... I used to go to the toilet at the bottom... that was usually alright but occasionally the er... but that one in the middle... if you couldn't get any further you had to go in.

Mrs Heathfield found her ability to bathe limited in hospital:

Mrs Heathfield: I didn't know because I didn't have me hearing aid in. She [nurse] was going to bath all those people in... well there was six wasn't there... she was going to bath the six people you see well I was going down to be washed I said to her: 'Do you think I can have a bath today please?' So she said: 'Alright you'd better join the queue we won't leave you out'... Well I didn't know they were going you see. So that was like six she was going to bath... so I went in last you see and she run the water and it was quite cool... 'Oh' I said 'that's cold' you see... so she said 'oh its hot enough'... she was never really short with me but I think it was a bit too much for her doing six before breakfast you see... so I literally got dipped in and dipped out... sent back to me bed all wet she didn't let

me get dry or anything she just said 'put your dressing gown on' which was only a silky one... and I was absolutely wet and I had to dry behind the curtains at me bedside... but I had been dipped in [laughs]... but the others got their hair washed and everything... I didn't... anyhow I came out... that was on the Monday. I was out on the Wednesday... so er I was a bit unlucky but I must admit I was getting a good wash.

Clare: It's sometimes nice to get in the bath, if you've got half an hour three quarters of an hour... and it's nice and warm it can be relaxing can't it? ... Especially if you've got arthritis...

Mrs Heathfield: Well that's it... you see I can't use my arms... my arms and shoulders got... anyhow I got... I said to her 'Do you mind giving me back a scrub?' so I got that done... 'cos you can't at home can you... Well I've got a bath seat which lowers me down and I use me brushes to do the best I can yeah... but they were bathing them quite regularly really...now I should have said one afternoon 'Can I have a bath please', but they're usually sat down in the afternoon.

Clare: That's a good idea to ask in the afternoon.

Mrs Heathfield: Yes, they're more free aren't they in the afternoon. I would have got one... but I didn't like to.

Certain environments, both her son's home and the hospital ward, made managing her independence in relation to hygiene and elimination complex, and it was difficult to guard against threatened intrusion. The appropriate space and time needed was not readily available, in addition the limiting nature of the hospital environment compounded this problem. Mrs Heathfield also voiced some genuine health concerns, in particular, the

experience of sharing a hospital toilet with other patients during an outbreak of diarrhoea and vomiting on the ward.

Feelings of dependence therefore can be exacerbated by the limitations the hospital environment places on people. Although Mrs Heathfield was able to manage independently at home, in hospital she felt she was unable to bathe without asking for help:

I had to ask for one [a bath] because I go to the bathroom every day they didn't think I needed it you see.

4.2.1.2 Consuming support

Two sub-categories emerged during the analysis of experiences older people reported as they were 'getting home': *they'll do things for me if I need anything*, which reflects the experience of increased feelings of independence as a result of receiving support and *support threatens feelings of independence* which reflects the experience of support limiting feelings of independence.

'They'll do things for me if I need anything' Support increases feelings of independence

For some participants, access to appropriate support, instrumental, personnel or both, increased feelings of independence. Mrs Hodges felt she had adequate instrumental support, such as appropriate equipment and adaptations to her housing, to meet her needs and found this level of support made her feel independent:

I can do for myself. I have a shower that I can sit in and a good space around the toilet so I can get that in [indicates frame] and I can manage. It's a comfortable house the one I've got at the moment, everything's to hand.

Mrs Hodges felt supported by the personnel support she had access to:

They arranged for somebody to come in, morning lunchtime and teatime. In a way I like it better on my own but at least they do those things for me.

Others also talked about how a combination of appropriate instrumental and personnel support enabled them to feel independent. Mrs Heathfield lived in warden-supported accommodation and had adapted her home to her particular needs with the support of her friends, carer and voluntary bodies:

Mrs Heathfield: Everything I needed I already had it you see... I had that [referring to betaframe] which I walk very well with, I had the tipping kettle, I had that trolley [romatrolley].

Clare: This is a good idea as well [referring to magnifier for TV].

Mrs Heathfield: Yes that's a magnifier, yeah, that's very good.

Clare: Is that from the hospital?

Mrs Heathfield: No...er... Douggie [referring to friend in same sheltered home] he has one and they come and visit him you see from the blind.. He said oh you want to have one of these, you see well me eyes... I managed alright but they're not very good and that's very good for me so this lady came from the blind and she said oh yes... I had to buy it you see.

Clare: Was it expensive.

Mrs Heathfield: That was £80.

Clare: Worth every penny I guess.

Mrs Heathfield: Yes its very good... when she came about it she... they said it was twenty... by the time it came it was eighty... so she said to keep it and make sure I wanted it and I found it was very good so yes it was...well worth it yea.

Clare: I noticed you've got a phone with big... er.

Mrs Heathfield: Amplifier on.

Clare: It's got big buttons as well.

Mrs Heathfield: yeah big buttons hmm... they are very good, yeah.

Mrs Heathfield had many instrumental aids and help from a 'friend' who provided her with paid-for support:

Peggy does all my shopping for me and I pay her because she's just so good...I couldn't stay here without her...

Mrs Heathfield was proud of how she managed to stay independent but she appreciated the fact that without Peggy she would not be able to manage the way she did.

The instrumental and personnel support that Mr James received enabled him to feel more independent. He saw himself as mostly looking after himself but felt supported by his son Robert:

I look after myself mostly, although I have to say Robert is very good. He does my shopping, we go out every week normally, well I do see him every day and if there's anything wrong he'll see to it. But you have to do what you can for yourself.

Mrs Woodward returned to her adapted home and, initially, had continued strong informal support. She felt her home and other support arrangements were adequate for her to maintain some feelings of independence. However, her recent bereavement led to Mrs Woodward feeling unable to stay in her home:

Well... it is quieter... it was... well... with Fred [husband] not here...it seemed...well.

It was difficult to go back to. I didn't want to stay there, it was so empty.

She moved from an environment that enabled her to maintain feelings of independence to the un-adapted homes of her children, which compromised her chances of managing her own personal care.

On her return home Mrs Westerby received increased informal attention, as her family were 'keeping a close eye on her'; she also had daily care assistants who helped her with both domestic duties and personal care during the week. Mrs Westerby had help from her family to prepare and organise meals. With this personnel support and the appropriate adaptations to her housing Mrs Westerby found she could manage her life and feel more independent as a result of the type of support she had access to:

...with everything arranged the way it is, you see, we've got it so I can do for myself while they're not here.

Although she lived in a bungalow, Mrs Trent had little instrumental support:

Mrs Trent: Oh it's a lovely bathroom you know...I can manage on my own in there.

Clare: Do you have any special aids or anything?

Mrs Trent: Oh no I just get in there and bath you know.

Clare: Moving round the house, how do you manage moving round the house?

Mrs Trent: I've got my stick for this leg...there's nothing to see...I've got a bad leg...its inwards you know...arthritis type of thing.

Clare: And that's enough to get you round the house?

Mrs Trent: well I don't use it unless I'm forced [by circumstances] I get about, I'm alright you see. It's not a big place is it, it's a little bungalow.

Clare: It's very cosy.

Mrs Trent: Oh yes its lovely and warm. It's got a nice kitchen.

Clare: Do you have any special aids in there?

Mrs Trent: Oh no...just my usual kitchen you know.

Mrs Trent coped with her daily needs and, with the support of her family in terms of shopping and other domestic duties, was able to manage a quality of life that she felt was adequate.

Mrs Weeks coped alone pre-admission, with her stepson, Mark, to help in emergencies. Mark organised domiciliary care to give Mrs Weeks some extra support when she first got home:

You need a little help as you get older, but if you get the support you need you can stay independent.

I was pleased he [Mark] organised a home help for the first weeks home, you do need something when you first get back and I don't want him in here.

Mrs Andrews' proactive management of her formal support may indicate some feelings of independence:

Clare: Does anyone come in to help?

Mrs Andrews: Oh I did do...I chucked her out.

Clare: Did you?

Mrs Andrews: Oh yes I did ...I'm not paying for that for nowt.

For some, therefore the support they were receiving made them feel more independent.

Support threatens feelings of independence

This sub-category contains two experience codes: 'If anything goes wrong ...she'll put you in a home', which reflects problems arising as a result of the actions of formal staff that threatening feelings of independence and 'She does fuss', which reflects problems arising as informal support threatens feelings of independence.

'If anything goes wrong ...she'll put you in a home': Problems as formal support threatens feelings of independence

Mrs Branson fears failure to appear independent may have extreme consequences and lead her into a more dependent situation:

The only thing is with this warden. I have a horrible feeling that... if anything goes wrong 'out' [gestures with thumb over shoulder]... you know...she'll put you in a home.

This made it difficult for Mrs Branson to ask for certain help if her needs changed:

I couldn't say to my daughter I'm worried about having a shower 'cos she'd say 'Well you're not going home then mum'...you know.

Mrs Branson had mixed feelings about getting home:

Clare: Is it nice to get back?

Mrs Branson: Yes and no, yes and no. It's very, you know, I'm a bit shaky.

Mrs Branson's experience of recovering after her heart attack left her questioning how likely it was to happen again. Her concern with regards this reoccurrence meant that she felt she needed more help, for example, to attend her lunch club:

We have a dining club, about twice a week. Well... I can have that and they'll bring it to my flat, but before I used to go across to the centre and have it with everybody else, but I don't think I dare do that just yet 'cos I've never walked as far... 'cos its quite a distance... you know it's a full length of that ward and some... and some... and I can't even walk the length of that ward.

She talked about how she used advice from different sources when making decisions about how to manage her changing condition once home:

My daughter said: 'Why don't you try and get across there?'... The nurse that came the other day said 'Listen to your body, take it in stages...make the Centre your aim... your goal... take it in stages... don't expect to just come out of your flat and walk to the Centre 'cos you can't'...so I'm doing that ...I'm just... I haven't been out today 'cos I've spent the morning dozing [laughs] ... if I go down [fall] you see, there's a lot of problems, I'll be back in there and who knows if I'll get back on my feet after that. So I'm going to take things slowly, not rush.

'She does fuss': Problems as informal support threatens feelings of independence

Mr Charles was not keen on his niece, Pam, playing such a large role in his care at home. After his second discharge she made arrangements to provide as much care herself as she could, but this did not always suit Mr Charles:

Yes it's been fine, but she [niece] does fuss about.

Mr Charles allowed his niece to manage the situation as she saw best:

It's better to have my meals done and I don't have to bother about those things. I can't manage them anyway. If they want them done then they do them. So if you want to know anything about that you'll have to ask Pam [niece].

If I could do it myself they wouldn't need to come in. I've got all this you know this and that for the kitchen and getting round the place. I have done for myself but now I let her just do what she feels she has to.

Mr Charles was concerned by the amount he had to depend on his niece:

She [niece] does a lot... you don't like to feel like a burden so you do what [personal care] you can.

He was reluctant to accept help from his niece as he would rather not have felt indebted to her or restrictive of her life.

4.2.1.3 Living with support

Once home, four experience codes emerged as sub-categories. Two reflect positive experiences: 'He's who I call in emergencies' reports the experience where older people are able to access *support in a crisis*. 'They're popping in and out all day' reflects the situation where feelings of independence result from family support (*feelings of independence maintained through responsive family support*). Two sub-categories reflect reduced feelings of independence: 'It doesn't seem right' reports *feelings of dependence* and 'Rubbing along' reports a *reduced ability to maintain independence*.

‘He’s who I call in emergencies: Support in a crisis

For Mrs Weeks her step-son was “who I call in emergencies”. She described how he was available if she needed help, for example when she phoned him the night she was admitted to hospital:

...and he [stepson] came over, he is good you see, straight away. He cares for his wife but I couldn’t think of another night of it so I phoned him.

She managed at home with minimal organised support, indeed when her home help was arriving in the afternoons rather than the morning Mrs Weeks took on her own housework. Her home-help ‘continuing care’ scheme finished after six weeks but by then she felt as well as she had done before her recent illness.

Mrs Weeks received increased formal support immediately post-discharge but by eight weeks this support had reduced as she began to recover following hospitalisation. Mrs Weeks lived in a bungalow with no special adaptations. For the first six weeks home she had a home help daily, organised by her stepson. This was potentially supportive but Mrs Weeks found she had different standards and preferred to have her house tidy in the morning, whereas the home help came in the afternoon. By eight weeks after returning home, her daily help had stopped and she felt glad of this as she felt she could manage without formal support and did not find the daily help suited her:

During the first week she came every morning... and then it started to be in the afternoon... but I like to get everything organised. I like to have it all done for about half past one and then I can have a sit down with the house all tidy. It makes you feel better if your house is tidy doesn’t it dear... you can’t just sit there surrounded by mess... It can make you feel a bit, well not so comfortable. You can’t just let things fall apart because you’re feeling a bit off, so I like it all done in

the mornings... so I thought: if I didn't take those new tablets [prescribed analgesia] I wouldn't feel so dull in the head.

She preferred to manage herself by making personal adaptations to her situation, such as reducing her pain relief and strip washing.

Mrs Andrews felt independent at home, although she received no care from the warden:

That warden leaves you to it... it's all you... not them.

She did have someone to call in a crisis, which reassured her. However, Mrs Andrews wanted more formal support; although she had a home-help she found the support she received problematic and not always appropriate to her needs as she saw them:

No.. I still do everything, but it is love... it makes you tired, it knocks your stuffing out. And I wouldn't mind having one [daily help] but you have to pay and... so I have to do it myself.

Mrs Andrews felt she was used to spending time on her own:

Well I don't see many, I have to say. But I lost my husband twenty years ago and wasn't going to get another one, you never know with them do you? So I've been on my own a long while now and it's something you get used to. I like to see people but there isn't always that chance for us all.

She also found her reduced mobility and a lack of confidence impacted on her ability and wish to socialise:

I don't get out because I don't feel safe in doing it. If I slip, that's it I'm down and what do I do then? They do have a club on a Wednesday lunch-time but I can't be doing with it and it's easier to get on here [home].

Mrs Andrews' main social contact was with her brother:

I don't know that many people round here. I have lived here a long time, I've been in [the city] all my life, but people leave and pass on, and you find that its only really your family that you know. I do see my brother, we do the shopping on a Thursday, and he's a good sort.

'They're popping in and out all day': Feelings of independence maintained through responsive family support

Mrs Westerby had regular personnel support in the form of daily formal help supplemented with daily family visits during the week and care solely provided by her family during the weekend. She had an increased level of instrumental support in terms of mobility as her zimmer-frame was replaced with a roma-trolley. Mrs Westerby enjoyed a good quality of life, and felt she was independent within practiced limits:

They [family] help me keep going.... But I try to do what I can so they don't worry too much and it makes me feel better, pottering about.

After two months at home, Mrs Trent was happy with the amount of support she received from her family and formal sources:

Well it's just slipped back to the way it was, now I'm up and about. The home-help has been good though I must admit that was a help. I get by pretty well as things go.

Mr James felt aware of a reduced ability to manage his needs compared to how he had been before admission, but with the support of his family did not feel too dependent:

I can't do it all as I used to but I do get the help I need for most things off Robert [son], and my grandson comes over. They only live over there (points out the window), it's not too far.

I didn't have the, well, I was getting tired easily, so instead of going to indoor bowls they [Robert and the club] brought them here. I do enjoy my bowls and it's a good get together, it gets people out of their flats, it gets me out of my flat.

Yes, I am quite independent, as much as I can manage, but there's no good turning away help if you need it, though. It's best to keep yourself active, it keeps you younger.

Feeling independent was important to Mrs Heathfield and she did as much as she was able for herself. She saw it as a joint project: "We manage between us", although she was conscious of the limitations to her freedom, for example, pre-admission she often sat in her garden, however she lived on the second floor and could not manage the journey without help:

One thing is, it's very tiring. We do have lifts, and I would go if Peggy had the time, but she's busy enough.

Mrs Branson talked about the importance of managing for herself:

Well its best to keep doing those things for yourself, as long as you've someone who will help if you need it.

She felt she was able to manage with the levels of support she had:

It's a comfortable flat and I can do most things for myself and they're very good.

My eldest does most of my shopping or if I want anything you know and I do have a girl come every week to do the cleaning.

Despite feeling independent she was aware that she was treated differently because of her age:

But because I'm 80 people seem to think...people are just assuming that I've lost some of my marbles, that they've gone missing somewhere.

'It doesn't seem right': Feelings of dependence

Mr Charles continued to be concerned about feeling dependent upon his niece's goodwill:

Thing is now the way it's arranged now, if she goes away, or wants to go away it's a problem, I'd rather someone came in really 'cos then she could go away when she needed to and I wouldn't have to worry about it.

It's better now the help comes in at lunchtime, but to start with she [niece] was doing it all herself, and I didn't like that. We're not really a close family and it didn't seem fair to expect of her and well I would prefer it if I didn't have to have people come and help to be honest, well I'm glad of it, don't misunderstand but...

Mrs Selby was concerned for her husband's health and the load her needs placed on him:

He has looked after me for a long time, I've been in a wheel chair for a number of years, and I've other problems, with my heart, and he's always helped with my washes and he's been very good at running the house, better than most men would be.

Now, my daughters are still around to help but he can't help me get out of my chair, and he's always had to do that. So I don't know, he gets quite angry with my daughter when she tries to talk about things, so I don't know, and neither of us wants people we don't know in to the house.

These older people, despite experiencing good informal support in many respects, lacked control over how their need for support impacted on their carers. There was no co-ordinated collaboration between formal and informal support that was responsive to the needs of older people as they see them. Mr Charles continued to not get the support mix he would have preferred; Mrs Selby was offered formal support but at the time did not wish to upset the care relationship with her husband, despite her concerns for his health.

'Rubbing along': Reduced ability to maintain independence

This experience code shows how managing independence can be restricted by the physical environment but these threats can be ameliorated by an empowering, respectful and empathetic care relationship.

Mrs Woodward left hospital and returned to her own adapted housing, with an appropriate and accessible bathroom and toilet, which she shared with Tess, a 35 year old daughter, who had special needs, sight and hearing disabilities. She found living in her home difficult so soon after the loss of her husband, and after an unsettled period, Mrs Woodward and Tess stayed with one of her daughters, Susan, and her family in an un-adapted house. Mrs Woodward found it difficult to manage her continence and personal hygiene needs as due to her weight and angina she was unable to access the bathroom and toilet.

Mrs Woodward and Tess shared a downstairs front room, where Mrs Woodward also used a commode, borrowed from a friend. Mrs Woodward, with the support of her family, decided her daughter Susan should contact the social worker to apply for a grant to adapt her own home by converting part of the back of the house to an accessible bathroom, toilet and bedroom, in order to help her mother maintain her independence. This application was long and convoluted, little information was given to the family with regards to the process of their application and no time scale could be given.

Mrs Woodward felt there was little she could do to practically improve her situation and felt that her daughter was supportive and proactive in getting what she felt was needed:

Well, it's just a fact of waiting. She's [daughter] applied for everything she can, you know, but we've to wait for the work [adaptations on the house] to be done. Until then, you got to manage how you can.

Mrs Woodward described the situation they lived with while they waited:

We're rubbing along as best we can really. Tess has one of those high beds and mine is underneath like bunks, but we are used to each other by now. No we get by... it will be better when I can get to the toilet though. It is a bit difficult when we've got visitors and it's not always nice for Tess, she needs a bit to herself. But they're very good and I do feel comfortable. Thing is its difficult to get away from each other, not that we always want to but it would be nice for us all if we had a bit more space.

Mrs Woodward talked about how she, her daughters and the rest of the family managed her privacy and the importance of the sensitive support she received from her daughter in managing with dignity:

Well Susan helps with my shower. I get up there [upstairs to the bathroom] about every week, but mostly I just wash in here. We hang a curtain up at the door and I get a bowl of hot water and Susan leaves me to get on with it. You have to accept it when you need help ...and it's nice that we can talk about it.

It was difficult at first. I didn't like to say anything and then I'd have an accident and it made it all the worse. She [Susan] didn't flinch, that made it better, she just helped me sort myself out and we got on with things. It does make going out a bit awkward sometimes, I don't like it for her [Susan], but it makes it a bit easier that she doesn't complain.

Mrs Woodward talked about difficulties in managing her needs independently during the unsettled period before she moved in with Susan:

Here I can't get to the toilet but I am in a separate room. At [1st daughter's] I had to go in the front room, so it made it difficult if people were visiting, you know, they all had to file out and wait until I was finished. It wasn't very dignified.

Some people, you feel easy about letting them help, some people can be a bit brusque and that's not so nice.

Mrs Woodward's story reflects the problems imposed at a system level with regards to resources that are required to support an individual's independence, reducing their ability

to meet their daily care needs. Mrs Woodward found it difficult to maintain her independence at home without the correct environment and appropriate equipment. Although she had been assessed and it was found that she required adaptations made to her daughter's home, during the waiting time Mrs Woodward and her family had to manage difficult issues surrounding privacy. However, independence was managed through mutual compromise, in a supportive and respectful informal care relationship with Susan.

It was important, therefore, that Mrs Woodward and her daughters preferred that her support was provided by her close family. This personal preference, to be cared for by an informal carer, was being met for Mrs Woodward, and her ability to talk to her daughter about her problems gave Mrs Woodward some feelings of independence in relation to how her personal care needs were fulfilled at home. However, the slow formal response to Mrs Woodward's needs, in terms of both making adaptations to the home and in the lack of good advice and support from formal sources following her discharge worked against and so restricted Mrs Woodward's ability to take part in informed decision-making once home.

Mrs Westerby also faced restriction from the 'disabling environment' of an un-adapted home:

I get up in the morning and I get washed and dressed...but my daughter-in-law she does the bathing. I've put in for a walk in shower and they said they'll put it forward so how long that'll be I don't know...if it was a walk in shower I could do it myself do you see.

Some of these restrictions are ameliorated by formal and informal support:

Oh well the one [home help] that comes in the morning, she's brilliant. She's only young, but she really is brilliant. She says... she calls me Millie [nickname] like... she says: 'Is there anything you want doing? Are you sure? 'cos I won't be coming while tea time you know so.

Although Mrs Westerby was also supported by her family in managing her home and more demanding personal needs, such as bathing, she liked to manage as much as she was able herself:

I like to do it myself. There's a lot of things I like to do myself, you know...and it kind of keeps me happy I suppose.

Although she and her family were proactive in her application for alterations to her home, she had to wait for 12 months.

4.2.2 Discussion

A number of issues arise from these experiences. Firstly, that the context has a real impact on older people's feelings of independence and their ability to manage their own needs independently. The action of staff (for example in relation to the giving of laxatives and in relation to discussing problems arising from a hospital acquired infection evident on the ward) and the environment (for example available equipment and the layout of the ward) can impact on older people's feelings of independence in hospital. Instead of a stay in hospital acting as a 'pit stop', where older people's existing coping strategies are explored, supported and built upon, potentially leading to new creative solutions, being in hospital actually increases feelings of dependence and made 'coping' more difficult.

This tension is evident while 'getting home'. Consuming support can lead to feelings of independence for some and dependence for others. Those that discussed feelings of independence had access to certain capital (Bourdieu 1986) such as supportive informal networks or money and the cultural know-how to buy in the support they needed. These older people had access to flexible support that responded to their needs and access to timely adaptations or equipment necessary for them to maintain their independence. Those that referred to situations where consuming support threatened feelings of independence either felt that sanctions would arise from requesting help or that an inappropriate mix of carer type emphasised the need to 'be supported'. The threat of sanctions (whether perceived or real) resulted in care that was not responsive to changing needs and therefore represented a situation where a disempowering relationship with a formal semi-professional (the warden) made consuming support problematic. Receiving informal help when desiring formal help is the result of assumptions made, for example, about family relations and about which type of care was most appropriate. In addition this represents a situation where an older person's needs and wishes are not primary in support planning. Feelings of dependence can arise when older people do not have access to respectful, empathetic and empowering relationships with those that take part in their support.

Once home, many older people expressed feelings of independence through knowing that support was available if needed; this flexibility was often provided by informal support, although some older people found the 'emergency alarm system' provided them with some confidence in managing at home. The need to adapt support arrangements for one older person highlights the problems that arise when an older person's view of their needs is not central in decision-making. Problems continued for others and threats to feelings of

independence came from the type of care relationship available or limiting factors in the physical environment in which older people were living.

Two central dimensions emerge from the analysis of older people's reported experiences in relation to feelings of independence: the type of care relationships and the type of physical environment.

Type of care relationship: The first dimension that arose from analysis of the data and defined in part the category Feelings of Independence is that of 'type of care relationship'. This refers to how changes in support needs are met by changes in the care support available. Empowering support was experienced by a number of participants who discussed situations where care met changing needs, both increasing and decreasing levels of needs. These changes have been met in the main by changes in the level of informal care, but changes in the mix of formal and informal care were also reported. Participants who reported situations where the actions of carers (formal and informal) led to increased feelings of dependence can be considered as facing, in some respects, disempowering support. Therefore the type of care relations experienced is structured by how appropriate the mix of personnel support sources feels to the individual receiving care and the type of relationship dynamic, that is the level of trust, respect, empathy and flexibility that is experienced in the relationship with the main carer.

Type of environment: refers to how enabling or disabling the physical environment is in which an older person is living. Experience codes that reflect an enabling physical environment included those who lived in adapted/purpose-built homes and had access to equipment that was appropriate to their needs when they needed it. Many of the older

environment and referred to aspects of their home or the equipment they had been provided that either did not help or actually hindered feelings of independence.

4.3 Matters of Concern

A third category raised by those who took part in this project was that of concerns, worries, anxieties and fears.

4.3.1 Experiences of Matters of Concern

The concerns and worries of older people returning home changed across the discharge process for some people as different experiences were expressed during the preparation for home, getting home and being home. Three phases were identified in the category, namely: 'identifying concerns', 'identifying concerns while getting home' and 'concerns at home'. This reflects in part the temporal structure of the interview series but this is necessary in order to explore the changing nature of concerns during the move from hospital to home.

4.3.1.1 Identifying concerns

The main points of worry and concern discussed by participants in this study during the first interview (A: Preparing for Home), was associated with becoming aware of the potential situation they would face once home and the arrangements for, and the anticipated process of, discharge from hospital to older people's own homes.

'They might not worry about it but I do': Concerns not addressed during the preparation for home

Several issues were raised by older people during their preparation for home, that remained 'concerns' as they had been unable to discuss these with others and as a result were unable to access support in the management of the issues or the concerns they raised. The sub-category *they might not worry about it but I do* emerged during the phase

'identifying concerns' and reports concerns not addressed during the preparation for home. The following experience codes were included: 'concerns about immediate practical arrangements', 'concerns about medication', 'concerns about not managing once home', and 'financial concerns about paying for the newly arranged home help'.

Concerns about immediate practical arrangements

Many found the disjointed information given by doctors and nurses led to increased, and possibly unnecessary, levels of worry and concern. Being unable to give informal carers times for discharge heightened concerns about 'being a nuisance' to informal carers for some. Mrs Hodges described her experiences while waiting to hear about the timing of her discharge:

Mrs Hodges: Well I'm not sure when it [discharge] will be; they haven't said anything to me yet about whether I'm going home soon or not.

Clare: Did the doctors come round this morning?

Mrs Hodges: Yes but they didn't say anything to me. I tried to ask what was happening but they were busy today.

Clare: So no one has been to talk to you about getting everything sorted out at home for when you are ready?

Mrs Hodges: Well no, but I think I'll just manage as I usually do.

Once home, she reflected on her experiences of communicating with the hospital staff in preparing for home:

Mrs Hodges: But I was there [in hospital waiting to go home] a long time wasn't I, but Dr M., he never said anything. He just looked at your papers and just passed on to the next one.

Clare: You were a bit in limbo.

Mrs Hodges: I was, it was a peculiar feeling, and then he did start telling people they could go home, and then the tall thin one, whose name I don't know, said to me one afternoon 'Would you like to go home Mrs Hodges' and I said 'Oh yes please' [both laugh] and he smiled. The next day I was hopeful but he just passed me by.

Clare: Nothing else was said?

Mrs Hodges: Nope, not that day, not the next day. After a couple of mornings Dr M came and I don't think, no he didn't say to me 'You can go home'. I don't think he even spoke to me that morning. And the staff came and told me you see; it was a peculiar feeling.

Lack of clear information about when someone is going home can lead to worry that is unnecessary and could be easily avoided.

Getting ready for home led to concerns surrounding immediate practical arrangements such as finding house keys for access, getting food in for the first few days, liaison between formal carers, such as professional health and social care workers as well as semi-professionals (home helps, care assistants and wardens), and informal carers (family, friends, neighbours).

Mrs Andrews was concerned that she had no food in for her immediate return home, and that she would not be able to manage the shopping without help:

Mrs Andrews: The only thing is going to be... as I am now... as I can dress myself I'm going to get out of here, but understand I've no bread or anything in the house as I haven't been home.

Clare: So you need some help to get some shopping in?

Mrs Andrews: Yes, just getting me something in to see me over wouldn't I?

Mrs Andrews was worried about 'the hospital' letting her brother know when she was due home and felt alone in this concern, stating:

They might not worry about it but I do.

Concerns about medication

Two individuals in this project expressed feelings of concern about the medication they were being prescribed. No change in medication led to worries for Mrs Woodward, who was concerned that one of the chronic issues apparent on admission, dizziness due to bradycardia (slow heart beat), was as a result of the cardiac medication she was using. No change in her medication levels meant to her that her 'problems' had not been effectively addressed:

They haven't changed my tablets though, so I think I just keep taking them. But those heart tablets make me feel faint. I told them but they're not concerned with that.

Fuller information or the opportunity to discuss her feelings with medical staff would reassure Mrs Woodward or possibly highlight areas overlooked in her medical care. Despite her identification of the problem, the issue was not addressed appropriately as seen by Mrs Woodward. She therefore felt unsupported by formal staff in her proactive attitude.

Mr James also mentioned concerns in relation to his medication. He had been prescribed diuretics, the levels of which had been changed but he was not made aware of this.

Therefore, on discharge he received what he thought were ‘the wrong tablets’. This caused him great concern, but he did not want to complain as he did not want to seem ungrateful or be seen as a problem:

They’ve given me these [shows medication]. I’m not sure what this one does; they’re not the ones I went in with. When I got home these were the ones I was given, Robert is going to take me to the doctors, we’re going to make an appointment to check they’re the right ones, but they know what they’re doing and I don’t want to rock the boat, but taking the wrong ones might make things worse. Well it wouldn’t help now would it?

Again, appropriate discussion and explanation of changes in formal intervention was not undertaken to the satisfaction of Mr James, which did not allow him the opportunity to give informed, and therefore legal, consent to the administration of medications.

Concerns about not managing once home

Mrs Branson was worried about the consequences of not managing independently once home. She worried that if she was unable to manage for herself she would be ‘put in a home’:

Mrs Branson: I don’t know about the bathing. I’m quite concerned about the bathing.

Clare: Are you?

Mrs Branson: Because it takes me such a long time to dry myself, and although there’s two seats, life goes on outside.

Clare: Yes.

Mrs Branson: And somebody might be wanting to come in my flat and do things you know and I’ll be in the shower and I won’t know they’re there... It’ll be

alright once I've had a [first] shower but I've not said anything to my daughter you know. Once I've had a shower I'll be alright but if I can't do it myself I'll have to have someone come in and do it for me.

Clare: Will you feel alright about talking to your daughter about it? For example if you've tried it and you can't manage would you feel alright about telling your daughter that you can't?

Mrs Branson: Oh yes. The only thing is with this warden. I have a horrible feeling that if anything goes wrong 'out' [gestures with thumb over shoulder], you know, she'll put you in a home.

Mrs Branson did not want to ask her daughter for help before her discharge:

I couldn't say to my daughter I'm worried about having a shower 'cos she'd say 'Well you're not going home then mum'...you know.

Financial concerns: paying for the home help

Mrs Trent talked about her concerns surrounding her ability to pay for necessary care as she 'failed' the means test represented by the eligibility criteria:

But the only thing is if I have to pay them, I don't know if I have to pay them and they're a lot of money out of your pension aren't they? Some say it's £30 a week but I won't have to pay that will I? It'll have to come out of my pension but I haven't had any for three weeks.

Fuller information from formal sources would reassure Mrs Trent in relation to how she would be able to access the support identified as necessary by the medical team.

4.3.1.2 Identifying Concerns while Getting Home

After discharge, 'identifying concerns while getting home' looks at the concerns discussed by older people during the process of transition between hospital and home, and includes concerns arising during the first week back. The focus of anxiety changed. Many were happy to return to their own homes, and one respondent talked about how she felt no concerns (*no concerns expressed*). A second sub-category, *concerns not discussed*, contains two experience codes: 'they're both very busy really' and 'you feel a bit shaky': The first reports the bitter-sweet experience of older people relying on their families; the comfort of being able to rely on their support but the recognition that this was negotiated in respect of the other demands that existed on the carers' time. The second experience code, 'you feel a bit shaky', expresses concerns about readmission, including associated issues surrounding the reoccurrence of their condition, some of which were ultimately linked with the fear of dying, and concerns about falling, including anxieties about coping while feeling 'watery', 'washed out' and 'knocked off your feet'. Finally the sub-category *I didn't think of it before* expresses the situation where problems arise during the first week home that an older person had not considered during their planning for home.

'I'm not really anxious I'm just eager': No concerns expressed

Mrs Westerby did not talk about feeling worried or concerned during the interview series. In preparing for home, Mrs Westerby felt supported by her family, and appeared unconcerned about potential changes or new problems:

I'm not really anxious I'm just eager.....

To make myself more comfortable; I've just had a new carpet and everything. I paid £395 for the carpet and they said you just sink in it, which I like and a glass top table, which I always wanted, and a new television. So what more can I ask for? (laughs).

On getting home, Mrs Westerby expressed her feelings of being supported by her family in their determination to support her in her own home:

I said something about when I come out I think I'll go in a home... but they [family] said 'Over my dead body you will'.

She described the support she received in the past when concerned about her accommodation:

Mrs Westerby: I got one [bungalow] from the corporation on [local estate] but it was all open at the back and there were all sorts going backwards and forwards. Anyway he [son] came in one day and found me crying and I said 'ooh I can't stand it with all those strange men and women coming backwards and forwards'. So he went to the corporation and they got me this one.

Clare: Did it take long to come through?

Mrs Westerby: No. I don't know what story he told, but it didn't take long and he must have fought for this bungalow for me to get it the way he did. Here I'm just round the corner from my son; they're very good.

Mrs Westerby's feelings of being supported and her expression of 'no concerns' might the result of a number of factors: it might be a reflection of the relationship between the researcher and participant, in that she felt disinclined to divulge such personal information; it may reflect the age gap between us; finally, it might reflect Mrs Westerby's approach to life or be as a result of feeling supported by her family in a way that means her concerns will be approached sympathetically and proactively.

'That's a worry you know': Concerns not discussed

'They're both very busy really': Relying on family

Others were aware that those who provide informal support might be busy and may have other calls on their time. Mrs Manning was independent in her home normally, but felt weak on getting home. She was aware of the work her daughter, and wider family, did for her and that they had busy lives:

Well they're [son and daughter] both very busy really. My son's busy with the Golf Club and my daughter has her hands full, working and so on...but she was here Tuesday night and my son popped in last night to see I'm alright.

... I don't have to worry them, but can manage during the days. It means less worry for my daughter...but eventually, in a couple of weeks I expect and then, you know, I'll take myself off upstairs.

Mrs Westerby also expressed an understanding of the limitations upon her daughter:

You can't expect people to come round to see you all the time. They have other things to do. My daughter would be round more but she has her own things, work and that. You have to just get on with it.

Mr and Mrs Selby had an interdependent relationship and, as his physical disabilities worsened, their children helped him to look after his wife. Mrs Selby talked about being concerned for his health, and his reluctance to discuss the problem with her:

My daughters they help you know with most things and he [Mr Selby] does everything round the house he can manage; and I'm not to do anything you know.

He's been pushing me in the chair [around the house] 'cos I get puffed a bit if I try walking...but he's 90 and his knees give him pain you know...so, but my daughter has been here and that's made things a bit easier... she helps him help me kind of thing...we get by.

We have lived here for about seven years and he does for me mostly so we'll ... but he suffers himself though he doesn't say a word you know...doesn't want to worry me too much and that.

'You feel a bit shaky': Concerns about falling

Mrs Manning was initially not concerned about going home, describing herself as 'not worried', because she had a 'lovely supportive' family, however on her immediate return home she voiced concerns about falling:

Clare: Have you found any difference between now and before you went into hospital?

Mrs Manning: Well when you come out you feel a bit shaky don't you... a bit washed out and tired and then there's the quiet, after all that noise, it can be a bit...well you know. I have felt a bit weepy but you've got to get on as best you can.

.....of course I've got a wonderful garden but I haven't been able to go and sit in it for a while you know.

Clare: Why is that?

Mrs Manning: Well I am frightened I'll fall. I'm still a bit, well let's say I haven't found my full strength yet, but I do love to go and sit in the garden and I can take this [lifeline] with me so if anything happens I can still call for help. But no, I haven't been out since I got back. I'll rest a bit more before I'll try that.

Clare: Did they talk to you in the hospital about falling?

Mrs Manning: Well no, just said I had to be careful but they did get me the home help which now I'm grateful for. I mean I didn't ask or anything but they could see I'd need something.

Clare: How did you get about before you went to hospital?

Mrs Manning: I just used that frame [betaframe] it does very well but I get a bit puffed out you see and my legs go a bit sometimes; although it's a bit better now, the legs, but I still get out of breath... and that's a worry you know.

Mrs Manning was concerned about falling and coping while feeling 'a bit shaky', 'a bit washed out and tired' and 'a bit weepy'; these issues impacted on her experience of managing her new situation.

Mrs Branson found the idea of walking across to her luncheon club daunting:

But I don't think I dare do that just yet, 'cos I've never walked as far, 'cos it's quite a distance; you know, it's a full length of that ward and some, and some, and I can't even walk the length of that ward.

She was anxious about the consequences of a fall to her future health:

If I go down [fall] you see, there's a lot of problems. I'll be back in there and who knows if I'll get back on my feet after that. So I'm going to take things slowly, not rush.

Not addressing these issues and anxieties about falling can lead to a lack of confidence, heightening concerns about falling, resulting in reduced mobility and a reduction in the

quality of life. These fears played a part in Mrs Manning not enjoying time in her garden and Mrs Branson not joining the social interaction offered by her luncheon club.

‘I didn’t think of it before’: Concerns not considered

Once home Mrs Heathfield expressed considerable concern about the possibility of a return to hospital:

Well I do get short of breath in movement. I get a bit worked up. I didn’t think of it before, but now, I’m a bit frightened. I don’t want to go back into hospital again. I’ve had three weeks in December and three weeks this time and I’m just... I’m terrified. I don’t want to go back into hospital. I think that’s all I can say about coming back home. I’m not going out at all.

She was concerned about her condition worsening, and the possibility of a repeat attack:

[My] breathings not as good as when I came out in December. It’s steadily...its steadily got worse. I felt quite frightened at hospital [outpatient appointment] yesterday. I felt as though there was no air you know, the breathing. I was getting tighter and tighter here [indicates chest].

Part of her concerns about readmission was linked to her worry about future illness and therefore to issues of mortality. Mrs Heathfield cited a number of other experiences that have added to this ‘terror’ of going back to hospital. Mrs Heathfield talked about the conditions on the ward; being in hospital was a restless time for her:

You’re so near [to each other] aren’t you in the big ward; you’re just so near... there’s no sleep at night. It’s just I’m frightened I don’t ever want to go in again.

She described a recent experience that had increased these concerns:

He came in this gentleman late at night and there was only six beds and during the night... I had phlebitis up here you see [indicates the top of right thigh] and all of a sudden something was gripping it and it hurt me. So I jumped up in bed and here was this old man with a beard... when he came in I thought 'Oooh Dr Shipman'... but it was very quiet... well everybody was asleep... well I just absolutely froze... and the button was there to press but I couldn't press it... I just sort of sat up in bed and froze...

And then this naked figure walked to the next bed and leant over and felt all the next bed. Well the man didn't wake up he was sound asleep, and by then I pressed the button you see... but then this figure went to the door, the ward door... but the ward door was shut you see... so I saw him feeling it... and then this little voice said 'Help me please, please help me' It was such a nice soft voice... Well I'd pushed the button and they came and there he was you see.

.... any how they got hold of him, they got him back to bed and put a gown on but he never slept... well they went out of the... wherever they go, and she [nurse] said: 'Oh what a shock you've had. Can I get you a cup of tea?' and I said 'No it's alright'...

Well he got up again... gown off again... he climbed over the rails well I don't know how....'cos he was 91...

... and he was feeling all the wall and he knocked a big picture off... well they got very cross with him... they heard this picture drop and they came in... got him back into bed again and got very cross with him... and he said 'If I've done anything wrong I do apologise. Where am I?' Well he was blind ... So you've all this to put up with and you try to get better and... you get so worked up about it.

4.3.1.3 Concerns at home

Three sub-categories emerged in relation to concerns discussed once older people had been at home for eight weeks: *I would probably talk to her* reflects a situation where older people felt happy to discuss the concerns they had with family members; *on-going concerns* reflects concerns that remained and had not been addressed. This sub-category contains three experience codes, namely: 'being a burden', 'living with pain' and 'living with grief'. Finally, *what else is there?* reflects a situation where an older person found it difficult to discuss the concerns he had.

'I would probably talk to her': Concerns discussed with family

Mrs Woodward was central in the life of her family and, before the illness and death of her husband, her house had been a meeting place for her children, grandchildren and great grand children. During her husband's illness the house was 'kept quiet'. Shortly after her husband's death (within the week) she was admitted to hospital. Following discharge, she experienced a changing home situation, eventually settling with her seventh daughter (Susan). Mrs Woodward was then in a situation where she found it difficult to get time to herself and this was how she preferred it, enjoying all the "hustle and hubbub" of the house as she did not like to spend time alone:

I don't like spending so much time alone, I'm used to being a bit more in the middle of things and I get lonely a lot. I start to feel abandoned after half an hour.

I like it that Tess is here. I always know she's here, at night I can hear her up there [in the top bunk]. She's a bit deaf but if I bang on the bed she can hear me, if there's anything wrong there's always someone about to help me.

If Susan goes out and the girls are at school then Linda [another daughter] comes over and stays with me for the day. Paula and Carol [daughters] come over from [east of the city] and Lee [son] lives round the corner and pops in now and then. And there's Pam [daughter], although we've had a bit of a falling out over the car, so I haven't talked to her for a while, and Eileen [daughter] has moved away, so that's all of them. I don't talk to John [son]. I don't get to hear from him, although I hear what he's up to through Lee. So it gets quite busy here, the way I like it [laughs].

I can talk to some, but it's not the same with all of them, though if I had a problem I would probably talk to her [daughter]... talk about it. She's happy to help, you know.

On-going Concerns

Some concerns remained unaddressed, and the anxiety they generated continued.

'Being a burden': Depending on informal support

Older people in this project expressed different worries once settled at home. Concerns were expressed about day-to-day matters such as 'being a burden on family and friends'.

Mrs Hodges was aware of the pressure her own needs had placed on her daughter:

It bothers me a bit because it's taking her time, but she doesn't seem to let it bother her. She has a business and the children and her husband as well as her job.

Mrs Selby was concerned for the well-being of her husband, who provided her with daily support as she had been unable to manage without his help for a number of years:

He's not been too good himself lately. He was in hospital last year and hasn't got his strength back. I worry about him, I don't know if he'll take help off my daughter when he should. He's a few years older than me himself.

Mr Charles also expressed feelings of concern about the amount of commitment required from his niece to provide him with the support provision planned for him. He would have rather relied on formal sources of support, but felt 'over ruled' by his niece, who insisted on giving him the care post-discharge, that had been provided pre-admission by formal care assistants.

Living with Pain

Living with pain may lead to feelings of worry and this can heighten the impact of pain:

It can be frightening. If you can't sleep the pain can be frightening and you sit and think of all the things it could be and it can be worrying sitting on your own like that... (Mrs Heathfield).

Mrs Weeks found the pain killers she had been prescribed, although effective, limited her everyday life and made her sleepy. She managed this situation proactively, by reducing her analgesia dose if she needed to be alert. Regular review of analgesic cover is important as pain and managing pain impacts on an individual's quality of life. Although formal professional support was available through referral to the pain action team, Mrs Weeks did not receive a review of her analgesia.

Living with Grief

Mrs Woodward was admitted to hospital within a week of her husband's death. She returned home to her original address, but over the three months following her discharge she had left this adapted home and had moved between her children's homes a number of times, finally settling with one of her children in an un-adapted, overcrowded terraced house.

Mrs Woodward lacked the offer of key, professional help. Grief counselling may have given her the opportunity to work towards coming to terms with the death of her husband; welfare advice and housing support may have encouraged Mrs Woodward to consider her range of options. As she was a council tenant, a 'swap' or re-housing might have been possible. A lack of support in these areas had a negative effect on her post-discharge care as it resulted in her living in housing that was ill-adapted to her needs, a situation that left her more reliant on her carer.

This need to move from the home in which death of a partner had been experienced was not a reaction particular to Mrs Woodward. Mrs Westerby also describes how she found herself in a similar situation in the past:

We came to live [in the town]...we lived there for a number of years, but he [husband] had cancer and was slowly going down. He died there [in their house]; so when he died I said to the lad [son] 'I can't stop here' so he said 'Why? You've got it lovely here' I just couldn't stop.

Mr James' feelings of lacking appropriate company were linked with the loss of his wife a few years previously.

'What else is there?' Problems discussing concerns

Pre-admission Mr Charles was supported by a care assistant, who came in the morning to help him with washing and dressing and breakfast, at lunchtime to ensure all was well and to prepare lunch, and in the evening to help him to bed. Mr Charles lived in a partially adapted downstairs flat; he had meals on wheels daily and experienced limited mobility and shortness of breath due to emphysema. He had no close relatives pre-admission although a niece (Pam) had recently moved into the area.

While preparing for the return home, Mr Charles, with some support from his niece, considered returning to the pre-admission support arrangement of twice daily formal help:

Clare: Are you ready for home?

Mr Charles: Well my niece is here and she can tell you what's happening. I think it will be like, the arrangement when I came in. I get people to come in and do my wash and that. It makes it easier of me, to get them in.

Mr Charles: if I didn't have them [home support], if they didn't send someone round then I'd be in here, there's no one else I'd ask.

I was unable to contact Mr Charles during the first week he was at home, but I made contact during the second week (day 12). He had been back into hospital for six days. I talked to him during the first week after his return home following this second hospital discharge. He talked about what led to his return to hospital:

I lost my breath altogether. They said I hadn't been looking after myself but I was fine. The services didn't start till the Thursday and I came home on the Tuesday... My niece complained... No one was informed. Lucky for me she turned up, but to be honest I'd managed alright, I had managed. But in the end I lost my breath and I did need something, treatment or whatever.

This readmission led to Mr Charles' niece not feeling she could rely on formal support to care for her uncle. Although they were not close, and she had only recently moved into the area due to a new job, Mr Charles' niece now helped him with personal care, helping him in the morning before going to work, and again on the way home. This had put pressure not only on the niece but also their relationship:

I didn't want her to do it [provide personal care], but she said 'What else is there?' and I have to agree. I don't want to be in and out of hospital all the time and she says she doesn't trust them to turn up and worries what if they didn't, so now I do have someone in to help with the flat, and the washing but [niece] comes in and helps with the rest of it.

I would prefer if she didn't have to, if someone else could do it. It's not like we're close family and she's not my daughter. It doesn't seem right but what can you do if you need help? It would be better to have a nurse in really but she [niece] says she'd worry.

Mr Charles felt some discomfort with the fact that his niece had to help him with personal care; he would rather have formal support. However he found himself in a situation where he was unable to trust that he would get the support he needed from formal sources despite the fact he would rather not be cared for by his niece but would have been happier with more formal support. Although the late start of Mr Charles' support service represents a 'glitch' in a complicated support system, it had real implications for his experience of care, in terms of how formal and informal care interacted, in this case poor communication led to a relationship of mistrust that left Mr Charles in a situation of limited choice about who provided his personal care. The continued receipt of care from his niece despite his true wishes can be seen to represent a certain 'interdependency' within their relationship, as Mr Charles is looking after Pam's concerns.

4.3.2 Discussion

While preparing for the return home older people referred to a number of concerns that they had not discussed with those who help them. In many ways this is understandable as it is a time of change, and in ways ‘imagined’ change, as older people are not necessarily aware of how changes in their condition may impact on their ability to cope at home.

On getting home and being home a number of concerns were not discussed or raised by either the older people themselves or those who provided them with support. None of the older people in this project reported access to specialist help, for example grief counselling. Not addressing problems such as fear of falling, managing pain and grief can impact negatively on the health of older people. Central here are the two dimensions of ‘raising concerns’ and ‘response to concerns’:

Raising concerns: this dimension reflects the ability to raise concerns. This may be facilitated by an understanding and empathetic relationship with those who provide care and it may be possible to discuss issues that hold some level of threat or fear. This was evident for some, however others found themselves less able to discuss or raise these issues. Therefore the dimension ‘raising concerns’ includes the properties: concerns raised by the individual and/or carer, and concerns not raised and having no opportunity to raise concerns.

Response to concerns: this dimension reflects the response older people get to raising concerns. A positive response to raising concerns is supportive and can involve providing information, allowing time to discuss issues, access to appropriate advocacy and advice as well as the provision of specialist services such as counselling. In addition it represents action to resolve problems that may be identified through this process. A negative

response, not having help addressing issues of concern, was reported by a number of older people in this study.

4.4 Managing Change

The final category emerging from the interview data represents experiences of Managing Change. By looking at the experiences that older people had of managing their changing needs, it is possible to explore whether or not levels of support provision were responsive to the dynamic experience of being alive and continued to meet adequately the self-defined care needs of the study group in a sustainable way. This category looks at the experiences of older people during the discharge process in relation to the changing support provision to which they had access.

4.4.1 Experiences of Managing Change

Where Making Decisions talks about planning and decision-making in relation to arranging the return home, Managing Change looks at the implementation of that planning, to identify whether older people experience the support they feel they need. Four main experiences of managing change are evident. Two groups represent positive experiences of the process: those where older people experienced discharge with the support of others, and those who allowed others (generally family members) to manage this process for them. Two groups represent a less positive experience, those where managing change was made difficult by the impact of support arrangements, either instrumental or personnel, and finally the experiences that reflect occasions where change has not been managed adequately, for the comfort and possibly the health of the older people reporting them.

Many experienced an increased need for support when first home. Half of this study group felt supported during this period by their family. Those without such support, or with limited access to it, relied more on formal sources. Having access to family support however, did not mean formal sources were not accessed. Support at home during the first few weeks came from a mix of formal and informal sources. How changes in an individual's condition and situation were experienced shaped their perception of their immediate return home.

Many of the participants in this study returned to home situations already adapted in part to their needs. However, some experienced a change in their care needs due to a change in condition and some had care needs exposed to formal view during their time in hospital which led to changes in their care arrangements. How responsive support was to changing needs and how appropriate this response was felt to be varied between individuals.

4.4.1.1 Managing change with the help of others

Support response as inclusive in the first week

Those in this group felt that their changing needs immediately post-discharge were met in a way that reflected their self-defined needs. Mrs Heathfield felt there was no overall change to her care needs, but felt a little 'fragile' on her return home and appreciated the extra time Peggy spent with her. Although Mrs Heathfield's long standing condition affected how she managed, she experienced no change following this recent episode:

Mrs Heathfield: I don't go out much at all... especially since my heart attack... and I do get a bit puffed out these days... but I am 83 and so that's how it is

Clare: When did you have a heart attack? That must have knocked your confidence a bit.

Mrs Heathfield: Well...about three years ago... and I didn't want to put too much strain on it so it would happen again.

No new changes were made to the instrumental support received by Mrs Heathfield following her discharge home:

Clare: Were there any changes made this time with how you manage at home?

Mrs Heathfield: No...everything I needed I already had it you see.

Mrs Heathfield had little contact with her family, who did not live nearby. She managed with support from 'bought-in help' which she funded and organised herself. She described how the visits from Peggy structure her day:

She comes every morning to see if I want anything...and...er then she comes again probably just after one o'clock...she makes sure I've always got something for me lunch....and she gets it out of the freezer if its in the freezer, for me 'cos bending's not so good....and then she comes again....you know round about five o'clock...makes sure what I've got for me meals....and then that's it ... er ... I'll lock up for the night... and that's my day.

Peggy helped Mrs Heathfield with a number of daily tasks:

Peggy has been driving for a long time. She's very good. She runs errands for me ... she posts my letters and that sort of thing.

... I get the same things and Peggy goes to Morrisons in the car for it. I can't do the carrying really... and going outside...well... you know ... er... how that is.

Although Mrs Heathfield was aware of the limitations to Peggy's support, she felt emotionally supported by her:

It's not so easy at home... where you have to ask for help off ... you know... like Peggy... She helps me but I can't have her there all the time. She likes to go out so she's not there always. I do feel a bit better because when it came to it I could phone her in the night and that was alright, so I think I'll be... I'll manage all right when I go home.

Mrs Heathfield was supported by formal, semi-professional sources during her first week home as she had access to support from the warden in her housing complex and arranged her own private support to suit her needs.

Mrs Hodges experienced a change in condition which led to an increase in self-defined care needs. She talked about how her condition had improved since being in hospital:

They have got me back on my feet again. When I first came in, well, I don't really remember it but I couldn't have done anything for myself. I couldn't manage to have walked about or anything. Normally I don't have any trouble but then, when I first came in I was very weak you know.

Overall, however, she felt her condition had deteriorated from before she was taken ill and required hospital admission. This had changed how she socialised with her family:

I wouldn't start lifting heavy pans or anything like that at the moment... people can pop in and we'll have a cup of tea. Whereas before I would have... the family would come and I'd have a meal ready or whatever, I'm not doing that at the moment. Jennifer [daughter] is very good, she'll usually bring something.

Pre-admission, she managed alone in her adapted bungalow with a daily home-help, but felt that for the first few weeks home she might need more support:

I manage fine with that around the bungalow [indicates trolley/frame] and when people pop in they'll do things for me if I need anything doing... I have a home help who comes in every morning... and she helps with the laundry and bits and pieces... but mostly I manage on my own.

Once home, Mrs Hodges experienced initial changes in both formal and informal support during the first week. Her daughter came to visit her more often:

Well, she was here yesterday from nine till about three. Peter comes on the weekends and she comes every week at the moment.

Even though her daughter was not able to provide help directly she was able to support her mother as she organised her services.

Mrs Hodges [Daughter] was saying that we'll get some of these meals ordered and the home-help will come in more often, you know...when I first go home

Clare: Is that to help around the house or does she help you with other things?

Mrs Hodges No, just around the house and the laundry.

Mrs Hodges' care assistant started to visit three times a day, a service newly organised by her daughter and hospital staff, and the frozen meal service delivered once every two weeks, organised for her by her daughter:

They arranged for somebody to come in, morning, lunchtime and tea time, in a way I like it better on my own but at least they do those things for me, and we've also got from [County] Farm Foods.

Changes in support after eight weeks experienced as appropriate

A reduction in support can represent an appropriate response as an older person recovers from their illness; reduced formal and informal support was experienced as appropriately responsive by almost half the research group. Mr James, Mrs Heathfield and Mrs Trent all experienced a return to pre-admission levels of informal support which they felt to be appropriate. Immediately following his return home, Mr James' son, Robert, visited more than once per day; by eight weeks this had returned to the pre-admission pattern of a daily visit. Mrs Trent's family reduced the number of times they visited per day; as she regained her strength she again began to visit her sister and friends. Mrs Weeks and Mrs Hodges both received increased formal support immediately post-discharge but by eight weeks this support had reduced as both began to recover following hospitalisation.

Mrs Weeks lived in a bungalow with no special adaptations. For the first six weeks home she had a home help daily, organised by her stepson. This was potentially supportive but Mrs Weeks found she had different standards and preferred to have her house tidy in the morning, whereas the home help came in the afternoon. By eight weeks after returning home, her daily help had stopped and she felt glad of this as she felt she could manage without formal support and did not find the daily help suited her.

4.4.1.2 Allowing others to manage change on your behalf

Support response managed by family in the first week

For people in this second group, defining their own care needs at this complicated moment in their return home was not possible and the majority of needs definition came from those closest to them, therefore part of their experience of responsive support was structured through the quality of communication within their relationships with their carers.

Mrs Manning felt supported by her family who lived nearby and took an active role in ensuring her care needs were met:

...everyday, my daughter rings every day, every day, and my son....yes...and I have five great grandchildren.....in fact my granddaughter brought two in here.

Yes I've got a marvellous family...they see to everything.

She [daughter-in-law] comes in during the week when she can but mostly I see her on weekends and the rest of the family you know... they all come over on the weekend... but they phone up to see I'm alright...

It's nice to have your family round you. I don't like to think how it must be if you don't have that.

Well, they both work you see and they have children and so they are busy...but my daughter was here Tuesday night and my son popped in last night to see I'm alright...but I've got this here you see [lifeline] and if I pull this or push this someone will come.

Mrs Manning's family also provided support to arrange meal times:

Oh my daughter sorts all that out... she does my meals and puts them in the freezer and I have to just warm them through.

Although preparations for home were disrupted by having to stay in over Mother's Day, her first week home was comfortable. Initially, in addition to informal support, she used

formal care offered during discharge planning and the hospital organised for a home-help to visit daily, a new service to Mrs Manning:

...they did get me the home help which now I'm grateful for... I mean I didn't ask or anything but they could see I'd need something.

Mrs Trent felt supported at home by her family:

I have a daughter who's very kind and I have a son...and me sister lives near hand you know" /.....she [sister] comes every week to see me like you know/.....She [daughter] deals with everything like, that what I can't get you know.

Mrs Trent talked about the type of support she received from her family and friends, for example shopping and company:

My daughter does that [the shopping] ... we haven't been yet mind but we will get ourselves organised... my daughter comes in and anything I want doing she does like.

I've had a man friend but he's very good... I came out [of hospital] Thursday and he was here and me daughter was here and her husband.

As she was restricted by her condition Mrs Trent saw the arrangement of a home-help as a responsive change to her support provision despite concerns with the expense. She found this change supportive:

Mrs Trent: Well she's very good she just does her work... you know...but some of them are so nosey aren't they?

Clare: How many times a day does she come in for you?

Mrs Trent: Just the once, just in the morning... you know, to tidy up like.

I was surprised that she was ...er doing what she did like 'cos I didn't know, I didn't ask for one... 'cos I've managed.

Mr James lived in purpose-built sheltered accommodation and continued to use a walking frame to move about his flat. Since his recent illness, Mr James had become more breathless and felt more anxious about how he would manage. He wanted his son to visit more often, but appreciated that he came in as much as he was able:

It would be good to have more company, but Robert comes as often as he can and it's good to know if there was any problems they'd be able to get hold of him quickly. He only lives over there.

He described how he managed with the support of his family:

Well I look after myself mostly, although I have to say Robert is very good. He does my shopping, we go out every week normally, well I do see him every day and if there's anything wrong he'll see to it. But you have to do what you can for yourself.

When he needed it, he could call on the support of his family:

When I'm not well, he [son] does most of it, and I have a grandson who lives not far from me, he takes me shopping sometimes if my son can't make it. But I'm lucky having them so close.

On his return from hospital and during the first week home, his son came in more often to help and reassure him. Robert also co-ordinated formal support services and restarted the home-help service that his father received twice weekly:

[My home help] has started coming in again so I just let her get on with it.

The warden was also supportive:

If there is ever a problem the warden can get hold of them in minutes.

Mrs Woodward experienced deterioration in her condition over-all despite improvements made during her hospitalisation and she was aware of how this had increased her care needs:

Mrs Woodward ... they all do a bit when they come round. I get out of breath.

Clare: Is that still a problem?

Mrs Woodward Well it is really...it means I can't always do everything but the girls are very good.

Mrs Woodward returned to a house, which she shared with her daughter, and which had been adapted to Mrs Woodward's specific needs. It had a walk-in shower, stair-lift and ramp access to the front door. Most of her large family lived nearby. She was confident of support from them once she returned home:

Well we're organised I think. I do leave it to them but that's so it's easier for them, I let them organise it all, the visits and that sort of thing, the way it best fits around what they have to do otherwise. It's been very nice to leave hospital, and getting back made me tired, but at least it's quiet here and I can sleep. But they've done all they should.

Once home, she settled well and felt supported by those members of her family that helped her at home:

Well yes, it was very busy yesterday; they've been by a lot of them. It can be quite a handful when the place is full, yes.

Mrs Westerby talked about how she had been in and out of hospital with the same recurring problem. Her changing condition made adjustments to support necessary. Before she was admitted to hospital, Mrs Westerby felt supported at home by her family and was able to rely on them to help her in emergencies:

I live on me own... but...I'm in distant call of me son and his wife so er.....I'm on the phone and the phone sits next to me so I've just got to ring. They're popping in and out all day providing she's at home 'cos she's a care worker too. She does days and other times she'll do nights... so during the night me son's always home.....so there's always somebody there I can rely on.

Her daughter and daughter-in-law also provided her with support for daily tasks:

I have a daughter who lives near [a local estate], she's working but she comes and brings me all me groceries and cleans me bungalow through on a Saturday. My daughter-in-law that lives a few doors away from me she does all me washing and any other thing that wants doing... so..... I've got plenty of help kind of thing.

If she's at home she cooks me tea...I get me tea cooked but otherwise I've always got plenty of frozen dinners and I can always put one of them in the microwave.

My daughter-in-law she does the bathing.

Changes in her needs she felt were adequately met by her family who offered more support post-discharge:

They're [family] kind of keeping their eye on me if you know what I mean.

Mrs Westerby relied on informal help for the general co-ordination of her care; her family used formal sources of support as they felt necessary:

Mrs Westerby: Well they do so much and then my daughter does so much... so I mean I've always got plenty to eat

Clare: Do you do any cooking?

Mrs Westerby: I used to do but not since I've had this second help...it's the standing up that's doing it.

Mrs Westerby: And it was my daughter-in-law that got the night visit... 'cos she said 'what's making you ill is stood there doing your tea'

Clare: Right.

Mrs Westerby: ... well now if she's on an early she'll do me tea

Clare: Yeah.

Mrs Westerby: er... if she's on a late rather... she does the tea. Then in the morning she brings mine in... and then both of us have just got to put it in the microwave.

Following discharge from hospital Mrs Westerby had a second care assistant visit organised; she found two visits per day during the week supportive:

Clare: Do you have any home help or anything supplied by the social services?

Mrs Westerby: No ... well.....just the care workers that come.

Clare: And how often do they come?

Mrs Westerby: They usually aim at my house for about half past eight.

Clare: That's every day?

Mrs Westerby: That's every day yes.

Clare: Including weekends?

Mrs Westerby: No, 'cos my daughter takes over.

Changes in needs met through informal support

Mrs Manning's family continued to provide her with the support she felt she needed at eight weeks post-discharge. They increased their visits and phoned her last thing at night to confirm all was well. Mrs Manning felt reassured and supported by this:

It's nice to see more of them and it makes the time I'm here on my own, well I know they are going to be... well someone is going to pop by if I have a problem, so ... and [daughter] or [son] phone last thing so I, if I need anything I can let them know. Ah it's all organised you see!

Mrs Manning lived in a terraced house adapted, prior to admission, by social services. Following discharge from hospital she had an emergency line service and a newly given roma-trolley:

I have one of those lifelines...you know I pay for it...but anything I'm able to have I take advantage of.

Mrs Manning felt her new trolley helped support her life at home:

.....they [hospital staff] organised that very easily yes... no trouble at all... so I can get in the garden you see.

Mrs Selby also felt supported by the increased time her daughters spent with her and her husband. Her initial concerns surrounding her husband's increased needs had been resolved by increased informal support. She felt happy that the problems had been resolved in this way and was confident that the support provided by her family would continue to meet her needs and respond to any changes in her condition:

With [daughter] coming in every day it's made it easier on him [husband]... he has help when he needs it and that has made things more comfortable for us both. I like the idea of [husband] getting help but we don't like the idea of people we don't know coming in and getting involved. We've always managed and like I say this isn't a new thing, but [husband] has always been able to manage until his knees.

Mrs Westerby continued to receive visits from her family on an increased basis. The rota used by the family pre-admission was adjusted to include more frequent visits on her return home from hospital and these continued at eight weeks post-discharge. The number of visits made by the care assistant increased from once to twice per day and this also continued at eight weeks post-discharge. Mrs Westerby felt happy with this and was reassured that changes in her care needs would be met through the support provided by her family:

How it is now, well they are very good. I see them often during the day and if they're going past they pop in. If I get worse they will see to things, you know if things change they might know before I do...

4.4.1.3 Managing change made difficult by the action of others

Problems with support response in the first week

For those in this category, not all their self-defined needs were responded to in a way they felt appropriate and decisions they had made were not always carried out. Mrs Andrews felt there was no change in the condition or levels of support and that the difficulties she experienced with the home-support service were due to the organisation of the service, not the level of service provided:

Nothing's changed really... they can't cure it [asthma] can they and I've had it for years. It's not usually that bad... what can they do... no it's much the same I manage the same.

Mrs Andrews lived in a purpose-built flat, with warden support. She had requested and been supplied with a walking frame, but it did not fit easily around her furniture, so she used it in the garden and kitchen and held on to the furniture to get about her house. Mrs Andrews had minimal support from her brother, but the support he gave her was vital. He took her shopping and helped in other practical matters, such as getting her pension during her first week home.

Before admission Mrs Andrews had daily help, with one home-help visit per day.

However she was not happy with the support she was receiving from the home-help and took steps to organise for home-help support that suited her. Despite this she referred to her need for more help:

Once I find a good help, then it would be better if she could help with a bit more, like the shopping and that, 'cos [brother] wouldn't have to come all the way over.

Mrs Selby talked about her reaction to changes due to being unwell:

I never really let anything really bother me when I was poorly... I just carry on the best way I could.

Once home she described how she was affected by the changes in condition she was experiencing:

Well I'm a bit cautious you know... I don't want to find myself in the same pain as before... I've been really careful and steady.

Mrs Selby had needed the support of her family for a number of years:

I haven't been able to walk for quite a few years, I'm in a chair you see... my two daughters and my husband help me at home... well my whole family does... they can do what they can and they can't do no more.

My husband's with me all the time... but my daughters pop in when they can you know.

Mrs Selby felt she was well supported by them:

Mrs Selby: My husband he does everything for me... 'cos I've got a shower... that you can walk into and that.. my husband will take me in there and put me on the seat and wash me and dry me and put me back in the chair and take me through and finishes me off...my hair and that you know

Clare: How do you manage with meals?

Mrs Selby: Him and my daughter do the shopping I can't do anything like that... and he does all the cooking.

However, she worried about how well her husband could manage:

He's ninety and his knees give him pain you know... so... but my daughter has been here and that's made things a bit easier... she helps him help me kind of thing... We get by.

My daughters they help you know with most things... and he does everything round the house he can manage... and I'm not to do anything you know.

But he suffers himself though he doesn't say a word you know... doesn't want to worry me too much and that.

Mrs Selby felt 'lucky' to have the help she did:

There never used to be anyone... if you were sick that was it... but now they take good care of you... and of course your family see to you... so that's... you know... the best thing really isn't it if you can't do for yourself and I'm lucky with my husband.

During the first week home, Mrs Selby was helped by her family, in particular her husband, and felt no need to access formal sources of support to maintain her daily life:

We don't need that at the moment 'cos my daughters and my husband manage most things... they did ask that we might need a home help but I'd rather not have people I don't know coming round to clean up I'd rather do it myself you know... no, we manage here.

However she did express concern that her husband had to manage despite his ill health and talked about the need to take up offers of formal help to reduce the burden on him. A fuller debate may have brought this concern to light and enabled Mrs Selby to structure her support with the inclusion of some formal help for her husband. Therefore, although informal sources of help felt responsive and appropriate, more formal support may have better suited Mrs Selby's needs.

Mrs Weeks felt she needed a little support for a short period after she returned home:

I've had it [her condition] a long while. I manage mostly, dear but I am a bit weak at the moment and I thought maybe having a home help will make things easier, just while I get back on my feet.

Mrs Weeks experienced a low level of family involvement in her first week home. Prior to her admission, Mrs Weeks had no home help as she had been managing with minimal help from her stepson:

Clare: So when you go home are you going to be back to doing all the housework and cooking?

Mrs Weeks: ... Well I always do... it's not a lot and I've got an automatic so it's not even hard work... if I take it at my own pace it's not a trouble.

I do all my own meals... I usually have a salad and something like corn beef or a boiled egg or something a little tasty like a bit of fish. I don't eat a lot dear but I like to eat what's healthy... and I have cod liver oil every morning... except I've been missing out on it here.

She explained the type of support she received from her stepson:

[Mark] comes and takes me to the shops once a week and I go and get what I want and he gets his shopping and then he gives me a lift back.

He cares for his wife... she has ME and she's diabetic as well so he's about a lot of the time... so if I needed something or it was an emergency it would be him I'd call on.

On her return home, her step-son had organised a home-help. Initially she found this supportive:

Although I didn't have much say in it, I was glad he'd organised it [formal support], although I think it was more for his benefit than mine dear. It seems like a good idea, although she actually arrives later than she needs to, so if I can get that organised then it would be better than having to ask Mark.

Therefore Mrs Weeks would have preferred a support arrangement that reduced the input of her step-son and allowed for more appropriate access to formal support. Along with this is the inappropriateness of the instrumental aids Mrs Weeks had access to; previously rails around the bath had been added with the aim of allowing her independence in meeting her hygiene needs. However, due to her condition and the inability of her arm to take any weight, this aim was not achieved; the bars around the bath for did not enable her to bathe independently, and she continued with strip washes.

Mrs Branson had mixed feelings about getting home:

Clare: Is it nice to get back?

Mrs Branson: Yes and no, yes and no. It's very, you know, I'm a bit shaky.

Mrs Branson's experience of recovering after her heart attack left her questioning how likely it was to happen again. Her concern with regards this reoccurrence meant that she felt she needed more help, for example, to attend her lunch club:

We have a dining club, about twice a week. Well... I can have that and they'll bring it to my flat, but before I used to go across to the centre and have it with everybody else, but I don't think I dare do that just yet 'cos I've never walked as far... 'cos its quite a distance... you know it's a full length of that ward and some... and some... and I can't even walk the length of that ward.

She talked about how she used advice from different sources when making decisions about how to manage her changing condition once home:

My daughter said: 'Why don't you try and get across there?'... The nurse that came the other day said 'Listen to your body, take it in stages...make the Centre your aim... your goal... take it in stages... don't expect to just come out of your flat and walk to the Centre 'cos you can't'...so I'm doing that ...I'm just... I haven't been out today 'cos I've spent the morning dozing [laughs] ... if I go down [fall] you see, there's a lot of problems, I'll be back in there and who knows if I'll get back on my feet after that. So I'm going to take things slowly, not rush.

Support Response experienced as problematic after eight weeks

Mrs Andrews wanted more formal support; although she had a home-help she found the support she received problematic and not always appropriate to her needs as she saw them:

No.. I still do everything, but it is love... it makes you tired, it knocks your stuffing out. And I wouldn't mind having one [daily help] but you have to pay and... so I have to do it myself.

That warden leaves you to it... it's all you... not them.

Mrs Branson faced the ongoing problem of the poor support, and at times, obstructive behaviour of the warden:

Oh well that's still the same you see. We don't have the same clubs that we used to and now I'm feeling a bit more like mixing... well it would be nice... but no, things are still the same. Of course I don't talk to her [warden] you see. I leave that to my daughter and son-in-law.

By eight weeks post-discharge Mr Charles felt the support he was getting from his niece was uncomfortable. He would have preferred to have had more formal care which would have reduced his worries about 'being a burden' to her:

I don't mind, well it's not perfect... she [niece] works hard but we... Well it's not always easy. With a daily, they sort out those things what need sorting and leave me to sleep if you like.

4.4.1.4 Unable to manage change

An 'Unsuccessful Discharge'

Of those that took part in this study, one can be seen as an 'unsuccessful discharge' in terms of the formal definition, as Mr Charles was readmitted within six weeks (Proctor *et al.* 2005) and also in terms of personal experience, as Mr Charles and his niece found formal arrangements inadequate.

Pre-admission, Mr Charles had some formal semi-professional support in a weekly home help. He had little family, and was visited by his niece who had recently moved to the area, but was frequently away from her home due to her work. Mr Charles was admitted to hospital with stomach pains, due to constipation. Treatment in hospital had resolved his immediate medical problem, but the reason for his admission led to concerns among formal health care staff about Mr Charles's condition and how he was managing alone. During the preparation for discharge, some of these issues were explored by the staff nurse in her conversations with Mr Charles:

... She did ask and I told her.

Mr Charles talked about what he saw as appropriate care:

And I think I will need something for when I get back, I need help with the housework.

... and it's not always easy to get myself sorted out in the mornings and meals you know, so I would like some help around the house, once a week is not enough.

To meet these self-defined care needs and to satisfy formal professional concerns, the support provision, through the discharge package organised by formal staff with some consultation with Mr Charles and his niece, included three visits from a care assistant per day (morning, lunchtime, evening) and home-help visits were increased to three times weekly:

She [niece] was telling me they were going to get someone to come and do housework jobs. I'm hoping for someone to do my meals as well... we'll see.

Mr Charles felt at least consulted about his care needs and the support he needed once home. His niece had also been involved in the planning of his return home and had explained that she was going to be away for four days due to an unavoidable work commitment. However, Mr Charles was discharged home while his niece was away. Communication between formal and informal support sources, health and social care workers, and hospital and community staff failed in this case. Mr Charles spent three days alone, with no support services, until he was discovered by his niece on her return from her work trip.

Mr Charles had experienced an initially smooth transition home. He returned home by transport ambulance, arranged by the hospital staff, to his ground floor, adapted flat, where he lived alone. However, as his support services did not start promptly, he was unable to cope. His niece called his GP when she visited on her return (three days after his discharge) and Mr Charles was re-admitted to hospital suffering from dehydration. Although his niece was concerned about the episode, Mr Charles seemed calm about the experience:

No one came for the first few days. [Niece] was making a fuss, I was alright I just slept anyway.

Mr Charles's situation changed between his first admission and his second discharge; both in terms of his care needs (as seen by him and his niece) and the support provision that was available to him. Although the initial problems with his condition that had led to hospital admission had been resolved, it exposed care needs greater than those met through existing support provision. At the request of both Mr Charles (on previous discharge) and his niece, the three home-help visits per week were organised by the

hospital. However, the support provision of three daily visits from a care assistant were declined by the niece, as she intended to reduce her work commitments and provide his care herself. Mr Charles talked about the sort of support he received from her:

[Niece] comes in every morning and at tea-time so... but really...I don't mind it, although I do see someone every day at the moment. [Niece] phones most nights, especially after last week.

Communication between formal and informal support sources was improved in some ways as Mr Charles's niece 'took control' of his second discharge home; however Mr Charles did not feel included:

No one really asked me what I thought about going home. They assumed a lot, but they didn't ask me.

Transition from hospital to home went smoothly, as he was driven home by his niece, who then ensured he was settled and fed, and stayed over that night to see that no problems arose. Mr Charles found this reassuring:

Well, it's nice to have that bit of reassurance, you know, just while you're first back. But I just want to sleep anyway really.

Disrupted Support

This experience code shows how poor advice and lack of counselling can lead to situations where support arrangements can threaten the health of an older person.

Although Mrs Woodward was the main carer for her dependent daughter (Tess), she had a large family that it was felt, by formal staff, could provide the support she needed at home.

Pre-admission Mrs Woodward had complex needs; she was overweight and diabetic with angina, which compounded her mobility problems. Mrs Woodward also experienced occasional incontinence but given enabling circumstances she could manage this herself. Before her admission to hospital, Mrs Woodward had a number of support arrangements; she lived in an adapted house that she had shared with her husband, until his recent death, and Tess, who had learning disabilities, restricted sight and hearing. She and her husband had been supported by two of their daughters who lived close by. However Mrs Woodward had experienced problems sticking to her diet, despite understanding its importance, due to the type of support she received from her daughters:

Mrs Woodward: Paula [daughter] takes me shopping every week... we do a supermarket shop...and if I run out someone goes and gets it for me... Paula brings meals round when she's cooked...but she's not very good with my diet.

Clare: Are you on a special diet?

Mrs Woodward: I have to not eat too much sugar ...I have all those no sugar things like jam... yuk... and I can't have chips too much either... but I love my biscuits.

Mrs Woodward: I shouldn't eat sugar.... Or takeaways...or biscuits...I don't mind a salad but Paula likes to cook... and Mary and Tess like takeaways.. I use that whatsit... Canderell in tea and I don't drink coffee... so that's fine.

Losing weight had important implications for Mrs Woodward's health as it would enable her to have a treatment to relieve angina symptoms:

If I lost some of this weight I could walk about more easily...you know... and not get pain in my knees the way I do now.

They will operate if I lose weight... I've got about three stone to lose.

Shortly after Mrs Woodward left hospital, she and Tess moved out of their adapted council rented home and moved from one daughter to another over a period of six weeks. Eventually she came to live with her seventh daughter and family (three teenage daughters and her husband), however Mrs Woodward had little contact with formal support since she left her council rented home. Assumptions made about the informal support network and the lack of support with her bereavement compromised the implementation of her support plan and disrupted contact with support agencies. Lack of timely advice about her housing options left Mrs Woodward and her daughter effectively homeless which had potentially negative implications for her health, in relation to her management of continence, management of her specialised diet and addressing her problems with mobility.

4.4.2 Discussion

Older people have a range of experiences of returning home from hospital care. The balances of power in deciding what needs were to be met with what support impacts on older people's experiences of managing change. This is evident amongst those that found the support they received met their needs and was responsive to changes. This was accessed by some by pro-active management of changes, calling on others to help in relation to certain issues and being able to pay for equipment or appropriate housing to make this management possible. A number of older people allowed others to manage the changes associated with returning home on their behalf. This was achieved through supportive care relationships that provided access to negotiation in the definition of needs and the choice of support measures to best meet these needs; in addition these care relationships provided responsive support.

Others found that problems arose when managing changes during their return home. Certain issues impacted on some older people's experiences, such as having problems with equipment that did not meet their purposes or formal semi-professional help that proved more problematic than helpful. Others found the management of change taken out of their hands resulting in a mix of 'personnel' support that did not meet their needs as they saw them or the threat of homelessness and all the implications this brings. One central defining dimension was apparent: approaches to managing change.

Approaches to managing change: a range of ways of managing change was apparent among the experiences discussed: managing change with the help of others, allowing others to manage change on your behalf, managing change made difficult by the impact of support arrangements and unable to manage change.

4.5 Matters Arising: Discussion

Four main categories were identified during open coding: Making Decisions, Feelings of Independence, Matters of Concerns and Managing Change. Each category is divided in three, representing temporal changes as older people pass through the process of moving from hospital to home. Experience codes either emerged as or were subsumed under sub-categories; this second group are shown as indented on the table below. This process allowed for the definition of the sub-categories, and therefore categories themselves, to be made (see Table 4.2 below). In addition, a preliminary definition of the dimensions that organise these properties can be made in order to further define each category. This analysis continues in Chapter Five, where the dimensions are identified in relation to research and policy and a core category is defined.

Category: Making Decisions

Planning	Active in decision-making Family supports decision-making Planning managed by family Use of formal support Planning made difficult by the actions of others Problems with formal professional staff Problems with formal semi-professional staff Feelings of exclusion from decision-making Excluded by doctors Non-inclusive decision-making Disagreeing with doctors
Enacting	Active participation in transition Transition managed by family Problems with transition
Reviewing	Leading the decision-making Active in decision-making Decision-making supported by family Adapting available support Limited by the actions of formal support

Category: Feelings of Independence

Coping in hospital	Feelings of independence in hospital Recognising Independence Rediscovering independence Independence supported by family. Feelings of restricted independence in hospital
Consuming Support	Support increases feelings of independence Support threatens feelings of independence Problems as formal support threatens feelings of independence Problems as informal support threatens feelings of independence
Living with Support	Support in a crisis Feelings of independence maintained through responsive family support Feelings of dependence Reduced ability to maintain independence

Category: Matters of Concern	
Identifying concerns	<ul style="list-style-type: none"> Concerns not addressed during the preparation for home Concerns about immediate practical arrangements Concerns about medication Concerns about not managing once home Financial concerns: paying for the home help
Identifying Concerns while Getting Home	<ul style="list-style-type: none"> No concerns expressed Concerns not discussed Relying on family Concerns about falling Concerns not considered
Concerns at home	<ul style="list-style-type: none"> Concerns discussed with family On-going concerns Depending on informal support Living with pain Living with grief Problems discussing concerns
Category: Managing Change	
Managing change with the help of others	<ul style="list-style-type: none"> Support response as inclusive in the first week Changes in support after eight weeks experienced as appropriate
Allowing others to manage change on your behalf	<ul style="list-style-type: none"> Support response managed by family in the first week Changes in needs met through informal support
Managing change made difficult by the actions of others	<ul style="list-style-type: none"> Problems with support response in the first week Support response experienced as problematic after eight weeks
Unable to manage change	<ul style="list-style-type: none"> An 'unsuccessful discharge' Disrupted Support

Table 4.2 Showing the results of open coding as experience codes are organized as categories and their emerging subcategories

CHAPTER FIVE

MANAGING CHANGE

Chapter Five explains how the categories become more specifically defined as the dimensions that structure them emerged through the on-going process of open (substantive) coding allowing an exploration of the links within categories. The core category, Managing Change, becomes apparent through a process of theoretical (selective coding) in the final level of analysis, where the relationships between the categories are identified. In this way, a model can be suggested, that describes how older people negotiate the changes they face. Finally the central issues discussed in this chapter will be summarized

5.1 Links within Categories: developing dimensions

Chapter Four reports and discusses the range of experiences described by older people before, during and after their move from hospital to home. Open coding resulted in four categories emerging from the analysis of these experiences, namely: Making Decisions, Feelings of Independence, Matters of Concern and Managing Change. The dimensions of each category suggested by the data and the properties across these dimensions that organise the experience codes were stated. Chapter Five continues this analysis, to provide a definition for the categories (Glaser 1978) before addressing the issue of the relationships between the categories.

To provide a more developed definition of the categories, continued analysis is necessary to further clarify the dimensions; with the aim of “relating categories to their sub-categories” where dimensions can be seen as “the range along which

general properties of a category vary, giving specification to a category” (Strauss and Corbin 1998: 101), and properties as “concepts that stand for a phenomena” (Strauss and Corbin 1998:101).

Four categories, each with associated dimensions emerged (see Table 5.1). The dimensions developed through the process of constant comparison, as refinements were made to categories through continued data collection (in Interviews B and C, and memos made in the reflexive diary) and with reference to relevant research and policy literature only after older people’s views had been consulted and when theoretical sampling of ideas indicated this was necessary.

Making decisions	Feelings of Independence	Matters of Concern	Managing Change
Voicing needs	Type of care relationships	Raising concerns	Approach to managing changes
Role in decision-making	Type of environment	Addressing concerns	

Table 5.1 Showing the categories and their dimensions

In order to build the categories, it was necessary to relate experiences raised by older people in this study to experiences reported and models discussed in the wider research literature (Glaser and Strauss 1967, Glaser 2002, Strauss and Corbin 1990, Charmaz 2000), as well as to the provision made in policy and the implementation of this policy through practice. Therefore a summary of the development of the dimensions in relation to the literature and the policy that govern each area is included below.

5.1.1 Dimensions of Making Decisions

Two dimensions were identified across making decisions which were ‘voicing needs’ and ‘role in decision-making’. ‘Voicing needs’ refers to the ability of older people to identify their needs and make their opinion known and includes the properties: ‘being able to voice needs’, ‘negotiating voice’, ‘voicing opinions made difficult’ and ‘not voicing an opinion’. ‘Role in decision-making’ refers to the role of the individual and their definition of needs in decision-making and reflects the levels of inclusion in decision-making to which older people had access. This dimension contains the properties: view as central, view considered, view overruled and view excluded. The centrality of self-defined needs to the planning of support and decision-making is identified in research, and underpins both policy and codes of practice.

Ideas surrounding how to provide services and care for older people have recently focussed around notions of the participation of older people in the planning and provision of their own support services (JRF 2004, Powell *et al.* 2007) and consultation with older people as a user group in the production of support services (Hayden and Boaz 2000, NAO 2003, Audit Commission 2004). Although the central interest of this project was the experiences older people had at an individual level, policy, culture and economic factors shape the services and care available to older people and therefore represent a context within which older people made decisions about their care and support needs.

Policy is produced that reflects the communitarian principles of the New Labour Third Way; that is it conceives the relationship between the individual and the state as being one of rights and responsibilities and which requires the

participation and consultation of health and social care service-users when structuring and planning older people's support services (Hayden and Boaz 2000, *National Service Framework for Older People* DH 2001a, *Guidance on the Single Assessment Process* DH 2002a).

The way in which the policy aim of consultation and individual involvement in discharge planning impacts on an individual experience depends on a number of factors, including the way national policy is locally interpreted and implemented and the practice, attitudes and behaviours of not only the staff but also the informal supporters and the older person themselves.

5.1.1.1 Theory and Research

The importance of supporting older people in decision-making, especially older people who require and use support services provided through government has been explored in a number of ways (Andrews 2002, Glendinning *et al.* 2002, Crawford *et al.* 2002, Ross *et al.* 2004, Barnes 2005, Dunning 2005) that can be summarised on two levels; firstly at a personal level, as individual consumers of support services and secondly, issues surrounding older people at a system level, that is as a user group,

Research has explored participation of older people at a personal level and reflects concerns for the support of autonomy of older people during discharge planning and in the day-to-day experience of support. Support is more appropriate to the older person's particular care needs if older people are themselves involved in and consulted during the planning of post-hospital discharge services (DH 2001a, 2002a, McCormack 2004, Powell *et al.* 2007, Tanner 2007).

The notion of autonomy is central to the provision of person-centred care and care pathway and support planning (Leino-Kilpi *et al.* 2001, McCormack 2004). The role of the professional in planning and managing older people's support needs is, amongst other things, one of 'enabling' an individual's autonomy (Leino-Kilpi *et al.* 2001). Having 'choice' and giving 'informed consent' are part of a philosophy that strives to be anti-ageist where the enabling of autonomy is presented as 'socially just' and morally appropriate (Leino-Kilpi *et al.* 2001, McCormack 2004). As well as system level provision, through law and policy, this is also necessary at a personal level, in terms of combating ageism which will serve to increase respect for the older person's wishes and views. Autonomy is the basis of person-centred care and informed decision-making including informed consent (Leino-Kilpi *et al.* 2001). Two central and related elements are relevant here: person-centred care and definitions of autonomy.

Person-centred care

The person-centred approach apparent within policy (DH 2001a, 2006a) and good ethical practice (McCormack 2001) contains a concept of decision-making that is collaborative, participative and negotiated. The needs of the individual must be central to support planning in order to achieve provision that is needs-led not resource-led. In addition, the needs that structure provision are ideally self-defined, avoiding problems of the imposition of the professional view through assessment and assignment of support that follows professional concerns (Latimer 1998, Chevannes 2002). Professionals have an essential role when an individual feels unable to make decisions. Full and accessible information should be provided and older people should have the opportunity to discuss problems and possible solutions with a nurse/carer who has the relevant ethical and advocacy

skills to provide supportive needs identification through negotiation and by 'being with' the older person (McCormack 2001). This inclusive approach may be apparent between individuals and specific health and social care professionals on a one-to-one basis or within the more formal collaboration between the multi-disciplinary team, individuals, their carers and family members within the case conference (Moats 2006). The person-centred approach therefore conceives of power relations that are equal or patient –led, with the professional acting as advisor and facilitator (Martin 1998) and carer as 'executor' (Collopy 1988) of autonomously made decisions.

Autonomy

Autonomy has been described as a basic human right (*Human Rights Act 1998*), and an issue of natural justice. Central to the notion is 'self-determination' and self-efficacy (Hertz 1996); that is, 'the ability to choose freely' what happens to us, to be both consulted and allowed to make decisions about our lives, set our own goals, and live by our own beliefs and value systems. This freedom of self-determination is seen as synonymous with full adulthood in Western society (Hockey and James 1993, 2003) and central to a 'good quality of life' (Kane 2001).

The exercise of autonomy requires a number of factors such as being informed and understanding the situation and possible options as well as the psychological aspects, abilities and skills that enable self-efficacy. Different types of autonomy have been identified, for example Collopy (1988) produced a schema that included six categories within which he identifies a conceptual difference between personal

autonomy, that is the ability to make choices, and executional autonomy, that is the ability to carry out these decisions.

‘Autonomy’ as a concept has differing meanings (Hwang *et al.* 2006), which can vary between a notion of the freedom to choose from a pre-defined range of options to a view that includes the definition of the range of options as well as choice from that range made by the individual as seen as appropriate by the individual. The first is common in understandings of meanings of autonomy amongst professional groups, who see promoting proactive decision-making within person-centred care as a matter of providing options to older people that are both practical and meet the professional drive to minimise risk consistent with professional codes in the face of potential legal action (Kane 1988, Moats 2006). The second is apparent within literature produced by pressure groups such as Age Concern, Help the Aged and Citizen’s Advice Bureau and within academic work that explores the implementation of negotiated decision-making and reviews older people’s experiences of receiving care and consultation within that process. This second view critiques the first, exposing the power relations that lie underneath (Katz 1996, Powell and Biggs 2001, Powell 2001, Powell and Biggs 2003, Powers 2003).

Health and social care professionals work within a hierarchical structure. They must meet certain standards of assessment and care packaging that do not leave their clients at risk and they must work within professional guidelines, meeting ethical codes of practice. They therefore experience the conflicts and contradictions within policy and legislation that place as central both individual

self-determination and demand the minimisation of risk. Defining a range of options that fulfil conflicting criteria is complex and within itself limits in some ways the personal autonomy of older people (that is, the right to define options as ‘appropriate’). It is also complicated by compromises to professional autonomy that result from constrictive work requirements (Moats 2006). Therefore when older people make choices about their support provision and care needs that are not seen as appropriate to their risk potential, as defined by professional workers, a problematic situation arises that may threaten an individual’s right to choice and self-determination (Golden and Sonneborn 1998). Although it is an accepted aim to provide support that ameliorates and appropriately reduces risks faced by the older individual living at home (DH 2001a), ambiguous ethical areas arise, posing questions such as: should care workers override risky decisions made by older people despite this practice restricting autonomy?

These conflicts, as well as explorations of older people’s experiences of autonomy available to them in decision-making, give rise to the question whether policy, through its implementation and practice, provides the necessary opportunities that support real choice for older people, or are concepts of ‘choice’ and ‘autonomy’ used in policy to maintain ‘disciplinary control’? (Foucault 1977, Powers 2003, Powell and Biggs 2003).

Furthermore, notions of ‘choice’ and the proactive service-user enshrined in New Labour policy parallels a paradigm shift in health and social care that moves from a focus on ill health and treatment, to healthy living and prevention. Concomitant with this is a change in what is expected of the ‘good patient’ (Latimer 1997,

self-determination and demand the minimisation of risk. Defining a range of options that fulfil conflicting criteria is complex and within itself limits in some ways the personal autonomy of older people (that is, the right to define options as ‘appropriate’). It is also complicated by compromises to professional autonomy that result from constrictive work requirements (Moats 2006). Therefore when older people make choices about their support provision and care needs that are not seen as appropriate to their risk potential, as defined by professional workers, a problematic situation arises that may threaten an individual’s right to choice and self-determination (Golden and Sonneborn 1998). Although it is an accepted aim to provide support that ameliorates and appropriately reduces risks faced by the older individual living at home (DH 2001a), ambiguous ethical areas arise, posing questions such as: should care workers override risky decisions made by older people despite this practice restricting autonomy?

These conflicts, as well as explorations of older people’s experiences of autonomy available to them in decision-making, give rise to the question whether policy, through its implementation and practice, provides the necessary opportunities that support real choice for older people, or are concepts of ‘choice’ and ‘autonomy’ used in policy to maintain ‘disciplinary control’ (Foucault 1977, Powers 2003, Powell and Biggs 2003).

Furthermore, notions of ‘choice’ and the proactive service-user enshrined in New Labour policy parallels a paradigm shift in health and social care that moves from a focus on ill health and treatment, to healthy living and prevention. Concomitant with this is a change in what is expected of the ‘good patient’ (Latimer 1997,

Twigg 2002, Faulkner and Aveyard 2002). Traditionally the 'sick role' (Parsons 1951) required passivity, now proactivity is central to appropriate patient behaviour in policy. However this is not always borne out within encounters experienced by older people (Faulkner and Aveyard 2002), who are keen to avoid the label 'trouble maker' that will potentially conflict with their aim to access support. This leads to a confusing situation for older people who have not necessarily been able to develop the skills and confidence required to make and 'voice' complex decisions.

Feelings of autonomy are shaped by individual personal traits (Frankl 1965), such as levels of confidence, the ability to put one's own point of view, the desire and ability to define and express one's own needs, and the confidence and past experience to make informed choices about support provided to meet these needs (Hertz 1996, Castelluci 2004).

Lacking feelings of personal autonomy reflects low confidence, the inability to express feelings, negative past experiences in accessing and receiving support, a lack of ability or desire to define one's own care needs, feeling unengaged with support available, not wanting to be involved and a feeling that contributing is pointless as the opinions of the individual will not be listened to by those producing the care package or providing care, in the instant.

Research that has explored the participation of older people as a social group or service-user group has ranged from consultation in policy-making at the lowest level of service-user involvement; to participation and co-production in policy

making and service planning, at the highest level of service-user involvement (Arstein 1969). Older people taking part in producing policy is necessary for the care provision to be responsive to user needs and flexible to the changing attitudes of older people as a population group (Daly 2001, Simms 2004). Parallel to this is a growing concern with both the provision of support services appropriate to the older person and that support is structured in response to individual needs rather than fulfilling service-led and professional concerns. There is also an emerging focus on participatory research and the development of methodologies that are inclusive of older people themselves (Huby *et al.* 2004, Ross *et al.* 2004, Grout 2004).

Underlying these research programmes is a growing appreciation of the level and impacts of wider held cultural notions that can be seen as 'ageist'. Combating ageism is at the very root of empowering older people (Nolan 2000, Douglas 2000, Palmore 2003, Meara 2004). Research that explores notions of ageism highlights the need to change the cultural values of all those involved in the provision of support, including those who make (O'Donnell and Entwistle 2004) and implement policy (Douglas 2000, Daly 2001, Means *et al.* 2003, Roberts 2004), those who practice as professionals (Davies 2002, Webster 2002), those that work in a 'hands-on' situation who are employed by the services but are not members of a professional body (such as care assistants and home helps) as well as informal carers (family, friends, neighbours) and the individuals themselves (Kharicha *et al.* 2004).

Research investigating the levels of access individuals have to services describes how access to needed support can be hampered by a complex system of provision (Brown 2003, Platt 2004). Collaboration between health and social care has been explored (Brown 2003, Dowling *et al.* 2004, Parkinson 2004). Without breaking this 'Berlin Wall' between the two (Frank Dobson cited in DH 1998a), confusion will hamper older people's access to the services they need (Brown 2003, Platt 2004). However, Brown's investigation (2003) into interactions within multidisciplinary teams has pinpointed the primacy of the doctor in the management of, for example, case conferences. Complex interrelations between professional groups, reduces the strength of the notion of the collaborative multidisciplinary team and undermines attempts at inclusive policy, such as the SAP (Nolan *et al.* 2001, Daly 2001). Furthermore, inadequate or inappropriate funding works against this policy aim to 'provide a seamless service'. Schemes such as 'reimbursement' (DH 2003b) have been criticised for undermining the policy intention of full collaboration (Glasby 2003a, 2004, 2005).

Geographical variation in how the 'eligibility criteria' is applied leads to differential access to support for older people across the country (Kohler 2001). Lack of appropriate information leads to problems with regards to decision-making and providing informed consent and so may lead to a reduction in access to the support needed to manage at home (Dunning 2005).

Therefore, macro-level methods of 'enabling' access to autonomy within decision-making must be implemented at a personal level, through empowering day-to-day

relationships between older people and those that provide them the support they need to stay in their own homes.

5.1.1.2 Policy and Law

There are two main areas of policy that are relevant here: *Better Care Higher Standards* (Department of Health, Department of the Environment, Transport and the Regions 1999) and the subsequent report from the *Better Government for Older People* programme (Hayden and Boaz 2000); and the *National Health Service Plan* (DH 2000a) and the resultant *National Service Framework for Older People* (DH 2001a). Both these pieces of policy guided and structured the daily experiences of support for those older people living in their own homes and requiring help from health, social and, or, housing services. Empowered decision-making is central and policy seeks to provide access to this for older people receiving support.

Better Care, Higher Standards

Better Care Higher Standards: A Charter for Long Term Care (Department of Health, Department of the Environment, Transport and the Regions 1999) aimed to improve services for those people needing support or care over the long term and resulted from *Modernising Government* (Cabinet Office 1999). This document spelt out the values of New Labour's approach to service provision emphasising the importance of:

“working in partnership with you to provide the services you need;
involving you in decisions and giving you enough information to make informed choices; helping you to give your views through advocacy and other representative organisations; treating you fairly on the basis of need

and not discriminating against you on the basis of age, sex, race, religion, disability or sexual orientation.”

(Available at <http://www.archive.official-documents.co.uk/document/cm43/4310/4310-01.htm>. Accessed on: 23/2/2005).

Better Care Higher Standards (DH & DETR 1999) required that a charter for users of health and social services would be produced in collaboration with those service-users, laying out rights and responsibilities of health and local authority services and reflected the policy emphasis on user involvement both at a group and an individual level.

Recommendations from this group informed future service development and planning and the procedures for staff recruitment, training and development. Within this policy document, certain values are emphasised through their definition, for example *involvement* is defined as “service-users actively contributing to determining their own care and to the continuous improvement of health services” and *advocate* as “friend, relative, or professional body who supports you and can help you speak for yourself or speak on your behalf” (DH & DETR 1999). The *Better Government for Older People* project aimed to increase the consultation and participation of older people in research and commissioning services as well as developing policy (Hayden and Boaz 2000).

The National Service Framework for Older People

The National Health Service Plan (DH 2000a), the *National Service Framework for Older People* (DH 2001a), and subsequent updates (DH 2004a, 2006b) set out

policy aims for the collaborative provision of health and social care services, where health and social care workers and private providers work together in the provision and delivery of services.

National Service Frameworks were developed to detail how the *NHS Plan* (DH 2000a) would be implemented and how its principles applied to certain areas; amongst these is the *National Service Framework for Older People* (DH 2001a).

This framework promised that:

“...nursing care in nursing homes will be free, that by 2004 a £900 million package of new intermediate care services would allow older people to live more independent lives and breast screening to cover all women aged 65 to 70 years.” (DH 2001a: 8).

Eight standards are defined. Relevant here are the pledges to ensure that ageism is not tolerated (Standard 1) and to develop personal care plans for older people and their carers (Standard 2).

The aim of Standard 1: Rooting out Ageism is “to ensure that older people are never unfairly discriminated against in accessing NHS or social care services as a result of their age.” (DH 2001a: 4) In order to achieve this, age will not be used as a criteria for deciding on and defining need or targeting the support available.

Discrimination against any individual simply on the basis of age is being addressed in national policy. NHS organisations have reviewed local policies to ensure age-bias is removed or justified. Local councils and care trusts have a

responsibility to provide 'fair access', through a means test represented by the eligibility criteria (*Fair Access to Care Services* DH 2002c) to services whatever an individual's age. Eligibility criteria are needs-led and structured on the basis of levels of risk (DH 2001a). It is important to combat ageism in wider society as well as specifically amongst staff through education, staff development and training.

The aim of Standard 2: Promoting Person-centred Care is:

“to ensure that older people are treated as individuals and that they receive appropriate and timely packages of care which meet their needs as individuals, regardless of health and social services boundaries” (DH 2001a: 23).

To achieve this older people will be able to make choices about the support available to them through the use of a person-centred approach. In addition the appropriate assessment of needs and support will be made through the SAP as well as through integrated commissioning and the provision of services.

Consultation and feedback from service-users is sought in an on-going project to address any problems that arise. A comprehensive series of surveys have been undertaken that will inform service provision, and looking at a range of issues including: prompt access, respect and dignity, information and education, involvement and choice, physical and emotional needs, co-ordination of care, environment and facilities, health improvement and community involvement.

Local health organisations and social services use a SAP in assessing all older people with care needs (DH 2001a). This approach to assessment aims to “cut red tape and save older people from having to provide the same personal details and discuss their needs with a range of different agencies: to ensure “their needs and wishes lie at the heart of the process” and “to provide support to meet needs identified through...thorough multidisciplinary, interagency assessment” and to provide “the relevant services, in an integrated way”

(http://www.dh.gov.uk/en/Policyandguidance/Healthandsocialcaretopics/Olderpeopleservices/DH_4002286, Accessed on 26/06/04).

Both the *Local Older People's Charter* (DH 1999) and the *National Service Framework for Older People* (DH 2001a) and subsequent policy updates (DH 2004b, 2006a) emphasise a number of important factors about how New Labour views the service-user and therefore, the older people who are receivers of care. There are three main areas relevant to discussions of empowered decision-making: the autonomous, pro-active individual, the implementation of notions of consultation within person-centred care and the need for an anti-ageist culture where respect for the personhood of older people is expected and older people experience treatment and care relationships with formal staff that conceive of older people as full autonomous adults.

First, the individual is conceptualised in policy as pro-active, with responsibilities as well as rights, reflecting consumerist notions of the market in relation to the individual service-user. Running parallel to this is a societal shift towards people as consumers of health care (Hughes 1995) and a mixed welfare policy that

incorporates public and private provision. Means *et al.* (2003: 21) refer to the 'fashion of consumerism'; where there is an emphasis on 'customer care', increased access to information for service-users, an increased right to consultation and an increased access to complaints procedures; however, they point out that this is not the same as empowerment.

Secondly, the 'autonomous individual' is entitled to choice, which is accessed through informed decision-making within person-centred care. This requires the provision of relevant information, in a way and language that is accessible to older people and their informal supporters (DH 2000a, 2001a, 2004b, Dunning 2005, DH 2006a). At a personal level this can be seen in a policy commitment to person-centred care; with the care receiver's view being represented and consulted (with advocacy services available to represent those who are unable to represent themselves) in the preparation of specific care planning, such as during discharge from hospital to home. At a user group level, this notion of the user as a proactive, autonomous individual can be seen in the policy promotion of participation and consultation in the planning and structuring of provision.

Thirdly, a commitment to 'tackling ageism' reflects a commitment to the value of social justice, where people are not discriminated against on the basis of personal and social characteristics, such as age, gender, levels of ability, sexuality, race, culture, class and religious beliefs. 'Ageism' results in a lack of respect of older service-users as full adults (Hockey and James 2003), leading to relationships between the service-user and support provider that are neither trusting nor empathetic and therefore not conducive to the support of empowerment.

Combating ageism at a service level and more immediately for those older people receiving support in their own homes, at a personal level is central to the empowerment of the individual.

Policy therefore reflects the research that has been carried out through consultation with older people and the political ideology of New Labour that holds a politically structured approach to notions such as the relationship of the individual to society; the older person; equality of opportunity and notions of support and care. It is still apparent that consultation at a user group level is not always successful; they might be consulted but have limited power in setting the agenda and getting their point of view enacted by government (Quetzal Tritter and McCallum 2006).

Campaigns and reports that recommend and demand the introduction of free personal care (Sutherland *et al.* 1999, Age Concern 2003, Help the Aged 2002, 2009) have not been followed; despite the fact that it would remove some of the divisions that remain in the provision of support services for older people.

The rhetoric refers to a joined up, seamless service and collaboration between health and social care agencies, but the fact that older people's problems must still undergo the process of definition as 'medical' and 'other/social' works against this aim. This is also brought into sharp relief when looking at funding implications.

Health care (response to needs defined as 'medical') is free at the point of delivery; for example, nursing care in the home does not cost the individual receiving that care directly, but through taxes. Social support (needs defined as 'other/social') is means tested through the eligibility criteria, with some services, such as personal care, being paid for if the means test is met. Therefore, policy

may be in the language that is pro-active, person-centred, promoting choice and access to autonomy through the provision of information, but this is not the universal experience of older people who have support needs.

Health and social care policy produced by central government, such as *Better Care, Higher Standards* (DH and DETR 1999), *The NHS Plan* (DH 2000a), *National Service Framework for Older People* (DH 2001a), and following updates and progress reports (DH 2002a, 2004a, 2004b, 2005a, 2006a, 2006b) and government initiatives such as *Better Government for Older People Network* (BGOP) (Hayden and Boaz 2000), *Partnerships for Older People Projects* (POPP) (DH 2005b) and *Dignity in Care (Opportunity Age DWP 2005, A New Ambition for Old Age DH 2006a)*, provide between them a framework for support that assures respect and autonomy for older people to make informed choices and decisions about their own care. There has been a change in the approach of health and social care services, and as a result, a change in the approach to training of both care professionals and semi-professionals, and the practice that they carry out.

5.1.1.3 Practice

The ethical codes of conduct for health and social care professionals all include the ethical notions of patient/client rights to autonomy, respect and dignity.

However how much actual day-to-day practice reflects these values is dependent on the personality, beliefs, values and attitudes of the individual staff member, resources (time and equipment, qualifications and opportunities for future ethical training, staff support, staffing levels, appropriate physical environment) and the culture of the organisation and others with whom they work.

Nurses

The Code of Professional Conduct is produced by the Nursing and Midwifery Council (NMC 2002), the registering body for nurses which defines the shared values that underpin expectations of professional practice. It states that:

“In caring for patients and clients, you must: respect the patient or client as an individual; obtain consent before you give any treatment or care and protect confidential information” (2002: 2).

To fulfil this, a nurse must understand and be respectful of an individual’s right to make decisions about their care. Nurses are professionally required to ensure the dignity of patients and clients, whatever their gender, age, race, ability, sexuality, economic status, lifestyle, culture and religious or political beliefs. Nurses must focus on the needs of those they care for by maintaining appropriate professional boundaries and promote their interests through providing access to services or information.

Informed consent before any treatment or care is central to nursing ethical codes; patients and clients have a right to receive information about their condition and this information should be accurate and accessible. However, it is also important to be aware of a patient’s wish to know. In supporting decision-making, practitioners must be mindful of the fact that individuals are within their legal rights to refuse treatment (unless otherwise stated by a court).

The code of professional conduct supports notions of service-user participation, autonomy and the necessity of the provision of informed consent and choice. Two aspects are important in the implementation of policy through the actual practice

of professionals (Platt 2004): implementation of policy through understanding and inculcation of policy aims and the ethics of care and nurse-patient relationships

To implement policy that promotes anti-ageism and autonomy through person-centred care, professionals must understand the aims of the policy and reflectively (Schön 1991) address practices in their own care-giving and personal attitudes to ageing. The importance of ethical training for those working with older people can be seen when it is understood that policy is enacted by social actors in the moment of caring. That is, policy that promotes user involvement, notions of empowerment and autonomy requires skilled implementation by those providing hands-on, face-to-face support.

A respectful nurse-patient relationship is essential for sensitive nursing (Hogston and Simpson 2002, Mason and Whitehead 2003, Grandis *et al.* 2003). Central to this respectful relationship is the nurse's role in supporting an individual's expression of autonomy (including the 'enabling' of autonomy when an older person is not able). This is necessary both in the moment of decision-making surrounding discharge home, and in the day-to-day interactions as without this understanding older people may not have the confidence to voice their opinion, due to low self-esteem or dis-empowering experiences with services, or an individual member of staff, or other members of staff in the past. For an older person's point of view to be appreciated and incorporated in discharge and day-to-day arrangements, it has to be both voiced, by the older person, and heard by those who are supporting and caring for them. The best vehicle for this is respectful one-to-one relations between the older person and those that carry out their support

needs; that is a situation where the carer can ‘hear’ older people’s wishes both during discharge planning and during everyday care.

Doctors and Medical Staff

The duties of a doctor registered with the General Medical Council are, amongst other things, to: “respect patients’ dignity and privacy; listen to patients and respect their views; give patients information in a way they can understand; respect the rights of patients to be fully involved in decisions about their care; make sure that personal beliefs do not prejudice patients’ care” (General Medical Council 2001:1).

Therefore doctors are expected to promote an anti-ageist attitude to older people in their care, both in promoting informed decision-making at the moment of discharge planning, and in defining an older person’s ‘problems’ and needs as ‘non-medical’. As health care professionals they are expected to have respectful and trusting relationships with those in their care in order to understand, and therefore consider, the wishes of the individual older person in the management of their medical conditions and the support the individual may need to manage their medical conditions on a day-to-day basis.

Poor communication between individuals and doctors and between doctors and other related care workers lead to a disjointed or disrupted service. One issue is recurrent amongst this study group, and that is the requirement for older people to stay in hospital over the weekend awaiting discharge by the medical team. This is neither explained to the patient nor challenged by hospital staff despite being of great relevance to older people returning home. Many are helped in the return and

initial days at home by informal support sources such as family and friends. Those providing informal support are generally trying to integrate a number of complex responsibilities for example care, work and other family commitments. The weekend therefore represents an ideal time for informal carers to 'settle' the older person in, and ensure that they are available to spend time with the older person immediately after their return. The tendency for doctors to leave discharge until Monday therefore reflects the needs of the medical team rather than the older person, and leaves other support professionals, carers and older people themselves to manage the inconvenience.

Social Workers

British Association of Social Workers: Code of Ethics for Social Workers (2002: 2-3) states the values and principles of social work as committed to five basic values:

“Social work practice should both promote respect for human dignity and pursue social justice, through service to humanity, integrity and competence.”

Of interest here are the principles to: “show respect for all persons, and respect service users' beliefs, values, culture, goals, needs, preferences, relationships and affiliations”; to “safeguard and promote service users' dignity, individuality, rights, responsibilities and identity”; “foster individual well-being and autonomy, subject to due respect for the rights of others”; and to “respect service users' rights to make informed decisions, and ensure that service users and carers participate in decision-making processes”.

Research and policy emphasise the importance of an ‘empowering’ worker-client relationship and accept that it is included by the individual practitioner in their care-practice. This inclusion is enabled by the structure, resource levels and culture of the organisation in which they work. Best practice highlights the importance of a respectful and empathetic relationship between client and worker in order to promote autonomy and informed decision-making and informed consent.

Care Assistants

The General Social Care Council has produced a *Code of Practice for Social Care Workers* (GSCC 2002) and a *Code of Practice for Employers of Social Care Workers* (GSCC 2004). The aim of these codes is to encourage high standards of care and good practice amongst those employing and being employed as social care workers. A register of practitioners is also kept and breaking these guidelines can be the basis for disciplinary action.

Despite these codes, there is not always regular ethical training available for Care Assistants or home helps; both are involved in the hands-on care of older people during the day-to-day support. No qualifications are necessary to work as a care assistant, despite the high level of advocacy and relationship skills needed to provide respectful and empowering support, although careers development in many positions encourage studying for an NVQ qualification in care up to Level 3.

Care assistants, despite often being the formal supporters and carers of older people, do not necessarily receive ‘ethical training’ prior to practice and priority is

given to the practical skills required in nursing and care. In protocols governing professional practice, and in the expectations of employers and government monitoring bodies, an older person's access to autonomous, informed decision-making about their own care is central. Through ethical training of staff, these values might be more widely practised in day-to-day encounters between older people and their formal care and support providers. It is in these encounters that the confidence in the import of one's opinion, and the confidence to 'become empowered' and voice one's own opinion is built, and meets, through empathetic and sensitive negotiation, a balance between the priorities set by the individual and professional concerns in the planning of post-hospital support services and in managing day-to-day living.

However, despite this comprehensive coverage in Codes of Practice, a tension remains between these values and daily practice (Scourfield 2002); the notion of anti-discrimination on the basis of age may be firmly embedded in professional discourses, but professionals remain unclear about how to carry this out in their daily practice (Roberts *et al.* 2002).

5.1.1.4 Voicing needs and role in decision-making

Two dimensions emerge: 'voicing needs' and 'role in decision-making'. The dimension 'voicing needs' contains the following properties: 'being able to voice needs', 'negotiating voice', 'voicing needs made difficult' and 'not voicing an opinion'; the dimension 'role in decision-making' contains the properties: 'view as central', 'view considered', 'view overruled' and 'view excluded'.

The properties of 'being able to voice needs' and having a central role in decision-making are identified as important for the provision of appropriate support in research, stated as essential in policy and implied in codes of professional practice. In addition, the concern to give individuals a powerful voice in the structuring of support is evident on two levels: at the micro-level, with a focus on the individual experience, and at a macro-level as individual encounters exist within a policy and cultural context.

5.1.2 Dimensions of Feelings of Independence

Two dimensions were identified during the concurrent data collection and data analysis: type of care relations and type of physical environment. Type of care relations refers to the level of access older people have to empowering care relations, in terms of achieving the appropriate mix of formal and informal care (personnel support) and the type of power dynamic apparent in the relationship between those who provide daily care and those who consume it. This dimension contains the properties empowering and disempowering care relations.

Empowering care relations are evident when an older person organises an appropriate mix of carer types (formal/ informal) that provides them with care that is responsive to their changing needs. This can also be achieved by an individual's family on their behalf. Disempowering care relations are apparent when barriers result in an unsatisfactory mix of carer types and/or care relationships that do not respond to changing care needs.

Type of physical environment refers to an older person's access to appropriate instrumental support (housing type, equipment). This dimension has two

properties: an enabling physical environment, defined by timely accesses to appropriate instrumental support, and a disabling physical environment, that is as a result of delayed or reduced access to appropriate instrumental support. Access to empowering care relations and an enabling physical environment leads to increased feelings of independence as a result of consuming support.

5.1.2.1 Theory and Research

Notions of dependence and independence arise regularly in the literature surrounding provision of care for older people (McCormack 2004, Nolan *et al.* 2004). Definitions however, are varied. Independence is defined as being able to carry out the essential activities of daily living without the support of others. Dewing (2004) describes how functional ability and competence are used as a measure of independence. Dependence and independence are discussed in relation to one another, that is, they are relative terms (McCormack 2001, Nolan *et al.* 2004).

Valuing independence is seen as a central theme in both the academic literature and health policy (Clarke 2003). We live in a society where there is a great emphasis on individualism and independence. This is certainly true in New Labour philosophy where the responsibility falls on each of us to ‘stand on our own two feet’ and be productive members of society (Ferguson 2007).

Dependency has been defined as being unable to carry out the activities of daily living (Mahoney and Barthel 1965, Roper *et al.* 1980); including both the basic activities of daily living (BADL) and instrumental activities of daily living (IADL) (Coleman *et al.* 1993). Dependency has been described as a one end of a

continuum (Hockey and James 1993) where there is a relation between both dependence and independence and individuals lie between the two. Dependency has also been conceptualised as a 'relationship' (McLymot *et al.* 1991) that is one of inequality, where there are those that are dependent and who experience a loss of control, and those that are depended upon and so experience a loss of freedom (Davies *et al.* 1997).

A number of theoretical frameworks have been advanced to define notions of dependency and the dimensions and factors that reside within this definition. Clark (1972) described a range of socio-psychological and individual-psychological forms of dependency, defining types of dependence: dependency in a crisis (for example the loss of spouse or similar trauma); neurotic dependency (a pathological reliance on others) and developmental or transitional dependency (due to, for example, puberty, menopause or retirement). Walker (1982) describes four dimensions of dependence: Life-cycle dependence, physical and psychological dependence, political dependence and economic dependence. Both these schemas may begin to explore some of our understandings of notions of dependency but they are simplistic attempts to describe complex, socially situated understandings and do not reflect the dynamic processual nature of how we understand and act upon notions of dependence and independence, nor how understandings of dependence and independence are shaped by cultural and social definition and are not solely the property of the individual.

Wilkin (1990) produced a classification matrix of dependency referring to causes of dependency such as: life cycle dependence, dependence in a crisis, dependence

as a result of disablement, dependency as a personal trait and socially and culturally defined dependence. These causes are set alongside categories of need (see Appendix 5) in an attempt to expose and explore the complexity of the notion of dependence. Four main issues arise from these definitions and typologies of dependence and independence: the notion of interdependence, the concept of the disabling physical environment, empowerment and, in particular relation to older people, the notion of ageism.

Interdependence

Within the literature debate points to the interconnectedness in all our lives, suggesting that there is no such thing as dependence and independence but that we are all interdependent on each other (Bond *et al.* 1993, Hockey and James 2003). Everyone in a complex advanced society such as Britain relies on the production of, for example, food, clothes and fuel by others in order to maintain themselves and their everyday lives. Within this schema, dependency becomes a particular type of interdependence. It, therefore, no longer makes sense to talk of people as being ‘dependent’, but as exhibiting a particular type of interdependence. Bond *et al.* (1993: 259) describe dependency as a ‘subset of interdependency’ in the following circumstances:

1. Where individuals are unable to perform “a range of actions... assumed to be within the competence of full citizens”
2. “Where an individual is unable to carry out essential tasks with reference to personal maintenance, physical mobility, sensory functioning, mental stability and communication, both written and verbal”
3. “Where society by its laws, conventions, buildings and social institutions, places individuals in a dependent role or situation.”

This view of dependency takes into account, not just the particular characteristics of the individual but places these in relation to the dominant cultural and social structures within which a particular type of embodiment, that of an 'old person', is experienced (Hockey and James 2003). However, ideas of dependence and independence remain pertinent to older people's understandings and experiences as the concept of 'interdependency' has not percolated downwards and the older people here still experienced this dichotomy.

The Disabling Physical Environment

That dependency is not truly an individual quality but a condition that is 'amplified and indeed created' by the structure and organisation of society is described by Townsend (1981) when he refers to 'structured dependency':

"Society creates the framework of institutions and rules within which the general problems of the elderly emerge and are indeed manufactured"
(1981: 9).

The 'disabling physical environment' refers to the notion that it is not the physical attributes of the individual that places limitations on a person in their everyday lives but limitations in the environment that lead them into the position of 'being disabled' and therefore dependent (Oliver and Barnes 1998, Swain *et al.* 2003). This approach to understanding the limitations placed on older people by the physical environment takes a lead from the social model of disability (Burr 1997, Barnes *et al.* 1999). The social model of disability sees the physical environment as one aspect of the limitations placed on those who are labelled as 'disabled' by a disabilist society. The SEAWall [*sic*] model of institutional discrimination (Swain *et al.* 1998) for example identifies three central factors, attitudinal, environmental

and structural, that frame disabled people as 'dependent' and disabled. An 'inaccessible physical environment' is included amongst the environmental factors identified. The environment is viewed here as a source of disablement (Swain *et al.* 1998) in that many of our buildings and the physical structure of our society leads to discrimination against those who are not physically able in the dominant cultural understanding.

There is much debate that refutes the link between disability and old age as: disability is only a small part of the issues facing older people, not all people are disabled, and collaboration between disability research and gerontological research may strengthen the cultural notion that being old necessarily implies living with disability (Oldman 2002). However, much work in policy and in health and social care professionalism with regards maintaining independence in the older person includes notions of adaptation of the immediate living and caring environment to reduce dependency and promote independence amongst older people. This is especially true for those who are returning to their own homes as it is a professional focus to identify and provide aids that can be installed in the home to promote independence (*National Service Framework for Older People* DH 2001a, Mountain and Pighills 2003).

Empowerment

The concept of empowerment is relevant to this debate as a central issue within the category Feelings of Independence relates to the type of care relationship within which an individual and their carer are engaged. Empowerment has been defined in a number of ways. It can be seen as something one person 'does' to others (Maurice and Ronayne 2000); something only an individual can experience

and 'do' for themselves (Hwang *et al.* 2006); as the 'action' of health and social care professionals (Feste and Anderson 1995, Faulkner and Aveyard 2002); and a property as result of particular policies (Cheater 1999). Underlying these debates on the conceptual definition of empowerment within the care of older people is an understanding of a particular approach to power relations between individual service-user and the organisation or system. This is enacted through particular formations of power relations between the individual and their carers.

Traditionally the power balance between professionals (such as the doctor, nurse or social worker) and the individual (as patient or client) has been one that favours the professional, in line with a patriarchal approach that places the doctor as dominant. Foucault's notions of governmentality, power/knowledge, and 'technologies of self' provide a critique of this relationship (Powers 2003, Moats 2006).

The concept of 'governmentality' (Foucault 1977) can be used to identify health provision as a 'disciplinary power' that exerts social control, through the detailing of a national average of populations against which individuals are compared and support is structured to return anomalies to this conceptual pre-defined 'normal' (Powell and Biggs 2003). In the support of older people, the pressure of governmentality works, through care and risk assessments, against notions of the professional role as one which works to provide an empowering context within which older people are supported in their definition of care needs and options to meet these needs through person-centred support provisions. Furthermore, person-centred care, which aims to place an individual's wishes and understandings as central in the planning and implementation of support, rather than the need to

normalise a problematic situation, will not be achieved if decision-making is not user-led and support needs-led.

Foucault's notion of the power/knowledge complex (1977) as socially constructed provides a view that challenges the dominance of medical expert knowledge as the natural order and a given. The possession of specialist knowledge held by doctors and other care professionals provides the professional with a dominant role in power dynamics within the therapeutic relationship.

The shift towards the inclusion of consumerist notions in health and social care has led to a need to re-conceptualise the responsibilities and rights of patients and clients. As proactive consumers we are responsible for the health of our bodies and must employ 'technologies of self' to 'produce' ourselves as appropriate to full adulthood (Hockey and James 1993, 2003). 'Consuming' medical and other formal advice 'appropriately' is necessary to fulfil our responsibilities as service users. From this view it can be seen that the context within which older people make decisions provides a freedom of choice only to accept professional advice.

However the emergence of the current policy and practice paradigm sees 'good practice' as promoting choice and the informed and supported decision-making necessary to structure care that meets an individual's needs and promotes independence. This is concomitant with the inclusion of 'consumerism' within health policy, which has both been informed by and led to a re-conceptualisation of the relationship between carers and the 'cared for'.

Empowerment as a concept is used to redistribute power between the individual and the health or social care professional and is used in policy to step away from state interventionism and professional dominance to a role of the professional as a facilitator and advisor, providing information, support and choice to a diverse number of individuals with a diverse range of needs and self-defined desires. Empowerment therefore represents a particular approach to the power dynamics between older people and those who advise and support them that sees it as a relationship where power is equally shared at a minimum and at an extreme in the hands of older people themselves (Arnstein 1969, Martin 1998). Furthermore, an empowering care relationship supports older people's feelings of independence as they match their needs to available support through a professional approach to shared power.

Ageism

Ageism, the discrimination of people on the basis of age, is relevant to debates on notions of dependence and independence as it is a dominant cultural view that a relationship exists between 'being old' and 'being dependent' (Hockey and James 2003, Nolan *et al.* 2004, McCormack 2004). This perceived relationship has in the past been left unchallenged within health policy for older people. Indeed this notion of institutional ageism has been highlighted in *The National Health Service Plan* (DH 2000a) and more specifically in the *National Service Framework for Older People* (DH 2001a). Both these pieces of policy seek to address ageism within professional practice in health services provision and this is mirrored in policy produced for those social care professionals working within the provision of care and support for older people in the community (*Independence, Well-being and Choice* DH 2005a).

However, negative links between being old and being dependent are embedded in our day-to-day culture; this includes those who surround older people, informal carers and friends as well as professionals. Cultural understandings change slowly and although both laws and policy exist to reduce the impact of ageist attitudes on the individual, ageism nevertheless remains and potentially informs views and opinions of individuals within society. The need for support for older people is seen as a sign of 'dependence' (Lloyd 2006); this is not the same for all groups, for the label 'dependency' may be attributed to an older person who is unable to manage their laundry but not to a businessman who is unable to meet the same needs (Bond *et al.* 1993, Lloyd 2006).

To reduce the impact of ageism on the individual, understandings of dependence, independence and interdependence must be informed by ideas that old does not necessarily mean dependent (Hockey and James 1993, 2003), that 'dependency' in itself is not solely an issue of individual attributes but also involves limitations set by wider social and cultural structures (Davies *et al.* 1997, Clarke 2003, McCormack 2004, Nolan *et al.* 2004) and that notions of dependence and independence are articulated and defined in a complex dynamic process that are subject to change and negotiation and are not set static constructs that exist in any true form as 'social facts'.

It has been argued that the strict dichotomy in relation to definitions of dependence and independence should be avoided (Munnichs 1976: 4, Bond *et al.* 1993, Hockey and James 1993, 2003) and instead dependence and independence should be considered as aspects of a negotiated relationship between those that

need support and those that provide it including notions that see us all as interdependent. However the dichotomous division between notions of independence and dependence has some relevance as it exists in wider cultural day-to-day views of those involved in the support of older people, and it is potentially present in the understandings of some older people themselves. Cultural change is slow; ageism may be legislated against but that does not mean that people stop behaving or reacting in terms of ageist ideas. Furthermore, while we live in a society that privileges youth and beauty, ageism and the marginalisation of an individual on the basis of old age will continue. Older people live and experience the day-to-day within a society that sees old age as associated with dependency and dependency as associated with 'non-adult' or 'less than full adulthood' (Hockey and James 1993).

5.1.2.2 Policy and Law

Aims to promote 'independence' and reduce 'dependency' are central to *The National Health Service Plan* (DH 2000a) and policy guiding provision of care for older people (*National Service Framework for Older People* DH 2001a). These notions are embedded within a framework that conceptualises older people as autonomous adults, able and willing to be proactive in their search for appropriate care. These ideas of the individual reflect the wider, political understanding of the 'autonomous adult' in modern society supported by the ideals of individualism and self maintenance privileged in New Labour's concept of the 'active citizen', where citizenship demands a balance between rights and responsibilities (Dean 1999).

'Independence, Well-being and Choice: our vision for the future of social care for adults in England' (DH 2005a) proposes that older people should be 'free' to buy in the care they want or need to maintain their independence. This green paper proposes aims where:

- "Services help maintain the independence of the individual by giving them greater choice and control over the way in which their needs are met".
- "We provide services with an emphasis on preventing problems and ensure that social care and the NHS work on a shared agenda to help maintain the independence of individuals" (*Executive Summary* DH 2005a: 9).

Notions of independence and dependence are still prevalent within health policy, specifically with reference to provision for the older person. They can also be used when politically expedient. 'Care in the Community', introduced by a Conservative government (*National Health Service and Community Care Act 1990*) was based on the notion of promoting the independence of older people, but also served the purpose of reducing public spending. A recent example of this political use of ideas about dependence and independence can be seen in the move away from providing hot cooked food daily to those living in their own homes to providing frozen meals on a fortnightly basis. One of the main advantages put forward by the director of the meals on wheels service for this change is that it will promote independence amongst those living at home. This belies the reality of older people's experience as they enjoy the regular contact incidental to a daily delivery (Age Concern 2003).

5.1.2.3 Practice

Although research-based practice would necessarily involve the inclusion of theoretical developments in understandings with regards, for example, interdependency, those professionals that are involved in the assessment of older people in preparation for their return home or in the provision of care within acute settings (for example hospitals) identify the need for support in maintaining independence based on an individual's ability to meet pre-defined Activities of Daily Living (Roper *et al.* 1980, Hogston and Simpson 2002). It is still within the nursing vocabulary to refer to a patient as 'largely dependent'; promoting independence and reducing dependence remains the goal of nursing care (Hogston and Simpson 2002). Furthermore, care workers need support in developing an awareness of their own attitudes to old age. These attitudes must be explored reflectively to critically assess personal biases and work to reduce the effect they may have on professional practice (Mason and Whitehead 2003). Ethical training therefore is essential for all those working with older people.

5.1.2.4 Type of care relationship and type of environment

Two dimensions emerging within the category Feelings of Independence can now be more fully defined as the 'type of care relationship' and the 'type of physical environment'. A care relationship can be either empowering or disempowering; the physical environment may be enabling or disabling. To provide help that matches an individual's definition of their own needs and therefore support feelings of independence, older people must have access to empowering care relationships and an enabling physical environment. Empowering care relationships are achieved through a mix of personnel (formal and informal) support sources that is satisfactory to an individual's needs. Care relationships must be trusting, empathetic and respectful and, in addition, 'person-centred', with

shared power, to ensure that care relations are both empowering and responsive to changes in needs. An enabling physical environment is achieved through a mix of instrumental means of support (appropriate housing and equipment) and must be appropriate and timely.

5.1.3 Dimensions of Matters of Concern

Two dimensions are apparent within the category Matters of Concern, 'raising concerns' and 'response to concerns'. Both these aspects are identified as important issues in research, policy and practice.

5.1.3.1 Theory and Research

Worry is a common human experience that involves "an attempt to engage in mental problem-solving where outcomes are uncertain and potentially negative" (Li 2005:3). Hunt *et al.* (2003) identified two extremes in the approach to theorizing 'worry': the first involves a problem-focussed approach; and the second sees worry as a dimension of 'anxiety', a pathological problem.

Problem-focussed approaches are based on an analysis of coping strategies used by older people. Hunt *et al.* (2003) describe three types: passive strategies, such as distancing; intrapersonal strategies, such as 'acceptance of responsibility'; and emotional-focused coping styles, such as positive appraisal, an approach used more by women than men (Parker and Seymour 1998). Li (2005) provides a more pragmatic typology when she described areas of worry expressed by families as older people are admitted to hospital. Four areas of concern were apparent in 'family worry': medication, formal care received, the future of informal support and finances. This schema has some resonance with the study group, who raised similar concerns on discharge. Mr James and Mrs Woodward were concerned

about the medication they received; poor quality communication between older people and doctors led to concerns for Mrs Manning when she was waiting for a discharge date; other participants describe concerns about the suitability of informal care arrangements. Finally, Mrs Trent discussed concerns surrounding paying for the home support the doctor advised her she needed.

Where it is seen as a component of a pathological issue, worry is conceived of as a dimension of 'anxiety'. In this context worry can be seen as 'uncontrollable' and 'negatively laden' (Li 2005:3). Anxiety is a cognitive concept that represents certain cognitive affects which are more extreme than worry and which can be seen as a defensive response against perceived threat to well-being, self esteem and identity (Kvaal and Laake 2003). However this defence response can have a negative impact on physical and mental health (*ibid.*). Psychology, as a discipline, approaches the analysis of 'anxiety' as a personal response to external and internal pressures. For example, it provides models that reflect the dynamism between personal traits and aspects of personality; and state traits and aspects of anxiety specific to a situation (Izard 1972, Watson, Clarke and Carey 1988, Tellegen 1985).

Anxiety is a distressing personal experience, that impacts on physical, physiological and emotional health, and therefore can result in a reduction of 'quality of life'. It has been defined in terms such as: 'diffuse apprehension', feelings of uncertainty, worry, decreased self-esteem, feelings of helplessness (Kvaal and Laake 2003: 271). As concerns can develop into anxieties, it is important that older people's worries are addressed for a number of reasons.

Understanding and discussing with older people their worries may lead to the exposure of a bigger underlying problem (Li 2005). High levels of worry and anxiety can lead to physical problems, such as reduced mobility, and mental health issues, such as depression. Worry over one issue can lead to increased concern over another (Hill and Brettle 2006). Furthermore, not discussing older people's worries during discharge planning both reduces the effectiveness of their participation and threatens the sustainability of a discharge care pathway that does not stem from older people's own strategies (Roberts *et al.* 2002, Powell *et al.* 2007, Tanner 2007).

Anxiety states amongst older people appear to be under-diagnosed (Kvaal and Laake 2003, Loebach *et al.* 2005). This may be because patients may tend to conceal this type of problem and that these problems are difficult to diagnose (Kvaal and Laake 2003) as most older people with these issues are seen in the community rather than in specialised settings (Loebach *et al.* 2005). It is important that older people's concerns are addressed, as high levels of anxiety have been found to increase the likelihood of depression, especially amongst those with reduced mobility and complex chronic problems (Kvaal and Laake 2003) and this in turn can contribute to a higher frequency of worries and mental disorders. In addition these levels of anxiety and lack of well-being increase after discharge (Kvaal and Laake 2003).

Fear of Falling

Nursing research has explored the experience and management of fear associated with falls, the experience of falling and understanding what lies behind a 'fear of falling' (Legters 2002, Hellstrom and Hallberg 2001). Fear of falling (FOF) is not

only experienced by those with a previous experience but also older people who are concerned by the potential and worry about the risk and implications of falling; this was a concern for a number of older people who took part in this study. It can be considered as an ongoing concern about falling that ultimately limits the performance of daily activities (Tinetti and Powell 1993) due to the patient's loss of confidence in his or her balance abilities (Maki *et al.* 1991). This link between reduced confidence and reduced quality of life was experienced by Mrs Manning in her reduced access to her garden.

Fear of falling has also been described as a general concept that describes two dimensions: both a lack of confidence at avoiding falls and being afraid of falling (Cumming *et al.* 2000). Subjects in one study however, indicated they did not describe themselves as being "afraid of falling," but rather were "worried about" falling (Tennstedt *et al.* 1998).

A wide range of factors contribute to a fear of falling (Lawrence *et al.* 1998, McAuley *et al.* 1997) and being worried about falling can have a more serious impact than the experience of falling, in that older people's lives were limited as a result (McAuley *et al.* 1997, Cumming *et al.* 2000,). The prevalence of FOF was consistently higher among women than men (Maki *et al.* 1991). However, this difference may be a reflection of an underreporting among men due to the stigma attached to discussing their fears (Maki *et al.* 1991, McAuley *et al.* 1997) and the publicity surrounding osteoporosis, which is seen largely as a 'female problem' (<http://www.open.gov.uk/doh/osteop.htm>, Accessed 14/9/06).

5.1.3.2 Policy and Law

Policy guiding care of the older person must ensure that older people have access to psychological support through understanding and dignified relationships between service-users and formal support carers, as well as an organisational structure that makes provision for these needs mandatory, including a clear procedure for the referral of older people to those professionals with the appropriate skills and training to address their problems adequately. Two issues are relevant here, access to information and advice and access to counselling and effective advocacy.

Increased access to information reduces anxieties by allowing people some feelings of control over the situation they are in (Roberts *et al.* 2002, Andrews *et al.* 2005). National policy that promotes participation by the proactive service-user on a personal level (DH 2000a, 2001a) encourages older people to ask questions and express concerns and therefore provides the opportunity for the supportive team of carers to give time to address these issues. The requirement of informed consent and the philosophy of 'person-centeredness' reminds professional carers that the individual older person is an autonomous adult with the right to make decisions about their lives. This has led to a plethora of information leaflets, information sources and advice services (Dunning 2005) such as those produced by pressure groups (Age Concern, Help the Aged and Citizen's Advice Bureau) and by health and social care service providers available from the Patient Liaison Scheme (PALS). However, Quinn *et al.* (2003) state that knowledge of the availability of information and how to access it is low for older people as a group.

Policy that encourages participation on a system level (DH 2000a, 2001a), through the consultation of older people, both in research and evidence based policy-making, may help promote an organisational culture within both health and social care that reflects the importance to older people of addressing issues of worry, concern anxiety and fear. Within the person-centred approach to planning of their own care, older people are seen as the central actor and their needs as primary. Providing older people with access to formal advocacy (Hayden and Boaz 2000) is seen as the empowering way to assess and identify support needs, when they were unable to manage decision-making effectively,

The National Service Framework for Older People, standard six (DH 2001a)

which addresses the issue of reducing falls amongst older people, also discusses ‘confidence in not falling’ as an important factor in prevention (DH 2001a).

Access to support which addresses psychological issues appears limited amongst the study group. Although increased access to mental health services by older people is addressed by Standard seven of the *National Service Framework for Older People* (DH 2001a), this covers more extreme issues. However, access to counselling support such as grief counselling, as well as having a forum within which to raise issues about receiving support and changing needs, would provide older people with an opportunity to address initially small issues before they become more serious problems such as depression and anxiety behaviour (Hill and Brett 2006).

5.1.3.3 Practice

Receiving support where concerns, worries, anxieties and fears can be discussed has been found to improve well-being, reduce anxiety and increase the quality of life for older people (Kvaal and Laake 2003). Furthermore, supporting older people in addressing their concerns during the discharge process is not only an exercise in developing their skills in expressing their wishes but also allows them access to their rights and encourages participation (Doherty and Doherty 2005, Dunning 2005).

Nurses, both in hospital and in primary care (Kvaal and Laake 2003), and other health and social care professionals must give time and space for the older person to voice their concerns and talk about worries, anxieties and fears as well as providing both the appropriate information and the opportunity for older people to ask questions (Bull 1992, Bull *et al.* 2000, Dunning 2005). It is important then that formal and informal carers appreciate that older people may have concerns and worries they wish to address, so that practical information and appropriate professional knowledge can be made accessible as necessary. Time and space must be put aside to ensure the appropriate environment and context to preserve an individual's dignity and privacy when exploring worries and concerns (Bull *et al.* 2000). Appropriate and timely referral, for example, to psychological support or assessment, is essential to support older people in the management of their concerns and fears (Bull 1992, Quinn *et al.* 2003).

Issues that require support from the formal care worker range from mild concern to psychological issues such as anxiety and fear. Older people's concerns with

practicalities can be reduced through information giving; worries about condition, abilities and future progress could be reduced through a mixture of professional knowledge, reassurance and information about condition(s) including listening, referral to a counselling service and suggesting management techniques and coping strategies (Hunt *et al.* 2003). Fears and anxieties may have a psychological root (Kvaal and Laake 2003) which, although they cannot be removed can be ameliorated through therapy or counselling (Hill and Brettle 2006). In this instance, an understanding of the problems older people face by those that are providing support is essential, as is timely referral to practitioners with the skills to address psychological issues.

Managing this type of therapeutic relationship is skilled work that requires training and support for the practitioner. Training for both professional and semi-professional support workers is essential to increase older people's quality of life (Kvaal and Laake 2003). To be effective this training must emphasise the positive link between supporting older people in managing their concerns and increasing access for older people to an improving quality of life as well as providing practical ideas and approaches to ensure the desired support is achieved.

It is therefore well documented that discharge is an emotionally stressful time (Bull 1992, Roberts *et al.* 2002) and that access to clear and timely information and the opportunity to ask questions and have them answered in a way that is satisfactory to the individual reduces both the level and range of concerns and worries associated with the complex process of returning home from hospital for older people (Kvaal and Laake 2003).

Furthermore, it is important in the ongoing evaluation of individual care that older people's worries and concerns are listened to, as this may indicate certain areas where appropriate information has not been provided, or expose the need for further discussion. Access to accurate information in a way that is appropriate to the individual service-user is not only essential for informed consent to be given (Butler 2002, Philips 2002), but is also central in the process of the 'co-production' of support provision (DH 2000a, 2001a, 2004b). Naturally, not all anxieties can be managed by formal health and social care staff, but where it is possible to support older people with feelings of anxiety and specific concerns it would increase their feelings of control over their return home and would enable the production of support packages more closely tailored to the individual's care needs as they see them (JRF 2004, Powell *et al.* 2007, Tanner 2007).

5.1.4.4 Raising concerns and addressing concerns

The dimension 'raising concerns' consists of the following properties: concerns raised by the individual, concerns raised by carer and individual and concerns not raised directly due to perceived sanctions and concerns not raised as no opportunity was available. The dimension 'response to concerns' contained two main experiences, a positive and a negative response. A positive response is identified by the following properties: time to discuss issues, access to appropriate advocacy, advice and information when needed, access to specialist services such as counselling when needed, action taken where appropriate, having help to address issues of concern. A negative experience has the following identifying properties: reduced access to time to discuss issues, reduced access to appropriate advocacy, advice and information when needed, lack of referral to specialist

services such as counselling, no action, the 'wrong' action and not having help addressing issues of concern.

5.1.4 Dimensions of Managing Change

The central dimension defining the category Managing Change was identified as approaches to managing changes faced on discharge from hospital to home, containing the properties: managing change with the help of others, allowing others to manage change on your behalf, problems managing change and managing change taken out of an individual's hands. These distinctions are evident in research and addressed in policy and practice.

5.1.4.1 Theory and Research

Research that is relevant to this category includes the availability of and access to social care and the support it provides. The attitudes of health and care workers can be seen to impact on individual experiences of returning home (Atwal 2002, Huby *et al.* 2004). This was apparent in the study group as one participant was faced with an uncooperative warden and this poor relationship made the move home problematic.

An over-reliance on informal sources in the planning of support once home can lead to problematic situations where assumptions are made about family relationships (Finch and Mason 1993) and older people are reliant for their personal and daily needs on the kindness of family members (Lloyd 2006). For some people this represented barriers to accessing the care they felt they needed or would prefer, and a strain on personal relationships. Assumptions about family dynamics and the role of female relatives as carers (Finch and Mason 1993) can lead to practical problems with the implementation of a discharge plan or pathway

and lead to situations such as the ‘disrupted support’ experienced by one participant in this study.

Managing change once home is also discussed in research, in terms of access to and availability of support provision, of whatever type (Katbamna *et al.* 2003).

The financial constraints within which Local Authorities (LAs) work restrict the effective management of changing needs faced by older people once home. In this study group this included variable information, tight eligibility criteria cuts or restrictions in services, a provision and quality poorer than for other groups and the variation in availability of different types of support (Katbamna *et al.* 2003).

Older people’s access to support is also impacted on by the political ideologies and management styles favoured by local and central government. This can influence priorities in service commissioning leading to differences in support availability. Finally, the access of older people to support, to meet their changing needs once home, may be influenced by the quality of individual interactions between older people and professional health and social care workers (Katbamna *et al.* 2003).

Two central issues arise from this. First, the full and active involvement of all those providing support (formal, both professional and semi-professional, as well as those in the informal care network) is crucial in developing a care pathway that is both appropriate to individual needs and sustainable (Doherty and Doherty 2005). This participation must be genuine to achieve this outcome, that is, participation in the true sense of the concept (Arnstein 1969, Roberts 2002).

Secondly, differential access is not necessarily due to different individual need, but is impacted upon by a number of forces, such as the standard of inclusion of the individual (Huby *et al.* 2004, Doherty and Doherty 2005), the quality of relationships with those that manage access to formal sources of support, the adaptability and strength of relationships with informal carers and the standard of communication between all those who provide support (Huber and McClelland 2003). In addition financial and time constraints can reduce access to appropriate, autonomously chosen care arrangements (Atwal 2002, Bowles *et al.* 2003).

Hospital discharge is a complex issue that requires a ‘whole-systems’ approach (Glasby 2003a) which includes supported participation by the older person and their informal carer(s), the appropriate coordination of the patient journey, intermediate and transition care and housing, and adequate continuing and social care (Walker *et al.* 2007). However, despite the introduction of person-centred care and the Single Assessment Process, these issues are still not universally well addressed (Powell *et al.* 2007). Furthermore, assessing the implementation of hospital discharge procedure, to monitor standards and identify good practice, is made more complex by both the lack of rigorous measurement in hospital discharge outcomes (Coffey 2006) and the debates that underlie the provision of older people’s services that are not necessarily evidence based (Glasby 2005).

The category Managing Change raises a number of pertinent issues, namely the problems that arise with support in the long-term if individuals are not fully consulted or their wishes are not enacted, poor management of discharge planning by medical staff, the need for increased services immediately post-discharge and

the management of these services, and finally the impact of poor relationship management on the part of semi-professional formal support workers.

Furthermore, this category raises the issue of failed discharge and disrupted support.

5.1.4.2 Policy and Law

Policy that governs the management of change involved in leaving hospital and returning home focuses on the assessment of need and planning; implementing the discharge care plan/ pathway process for an individual and the structuring and responsiveness of the support package once home: that is, hospital discharge and social support. These two issues are intertwined as a policy aim is to integrate the provision of health and social services.

Moving from hospital to home represents a move from acute to community health care and in some cases a move from health to social care. This second aspect is of concern to policy-makers as they aim to provide a seamless service, a holistic approach through the integration of provision (DH 2000a, 2004a, 2006b). Hospital discharge is a complex area of policy (Walker *et al.* 2007), and has equally been a long-term focus for policy-makers, practitioners and individual older people (Glasby 2003a). Policies to govern hospital discharge have developed since the early 1990s.

The *National Health Services and Community Care Act 1990*, introduced by the Conservative government, made a number of important changes. Firstly, it placed the concept of 'choice' as central to the provision of health and social care services. The aim was to achieve the inclusion of 'choice' through the introduction

of the internal market into state provided services and the associated increased emphasis on private provision. This notion of 'choice' led to a change in the role of professionals and other support workers in the process of planning for and implementing both discharge and support packages once home. Instead of being the provider of services, professionals now took on an assessing and advisory role, in that they helped assess older people's needs and provide advice about how these needs could be met, allowing the individual the opportunity to choose which services they required and the source of provision. However, professionals continued to have the responsibility for assessing, planning and managing the coordination of discharge planning and home support. Therefore, formal sources have a responsibility to co-ordinate and over-see the provision an older person receives (*National Health Services and Community Care Act 1990*).

However policy intention was based on a limited definition of 'choice', that was seen as unproblematic despite a number of underlying assumptions that negatively impacted on older people's experience of receiving care and support. What level of choice was available to older people is unclear. Also, how older people were to access this choice is not overtly stated. Professionals were to act as advisors, but older people may find themselves in the position where they were unable to take the lead in decision-making for individual or circumstantial reasons or that the choice available to them is limited due to the private and public services available in their area.

Second, it addressed the issue of maintaining independence by providing the support necessary for each individual to remain in their own homes as long as

possible (Glover 2005), with appropriate support to be identified through assessment of older people's needs. This policy, which became known as 'Care in the Community', was criticised for a number of reasons. It had the effect of increasing the reliance on informal sources of care (Tierney *et al.* 1993). It has also been criticised as being a money saving initiative, reflecting the aims of the neo-liberal government to shift the emphasis from state as provider to individual as responsible (Waters *et al.* 2001) rather than a reflection of service-user needs for 'choice' and independence at home.

Thirdly, many criticisms were made in reference to the outcomes of this policy as experienced in practice (Waters *et al.* 2001) and were levelled at the practical outcomes of the implementation of this policy: such as poor communication (Jewell 1996, Smith *et al.* 1997), poor planning (Victor and Vetter 1988), inadequate consultation (Klop *et al.* 1991), an over reliance on informal support and poor service provision (Tappen *et al.* 1995) and a lack of focussed care (Congdon 1990).

Following New Labour's election victory in 1997, *the NHS Plan* (DH 2000a), the *National Service Framework for Older People* (DH 2001a), the associated *SAP* (DH 2002a, 2002b) and *Fair Access to Care Services Guidance* (DH 2002c) were developed and introduced with the aim to tackle age discrimination, to more clearly conceptualise the relationship between individual and state, to increase the concept of 'choice', to develop a notion of 'person-centred care' to increase access to autonomy for individuals and allow some say in how their services were structured and provided.

The theme of person-centred care with the individual as self-defining their own needs and identifying appropriate care solutions on discharge (Holloway and Lymbery 2007) was continued in subsequent New Labour policy review (*Independence, Well-Being and Choice*, DH 2005a, *Our Health, Our Care, Our Say* DH 2006b).

Maintenance of effective and responsive support once home from hospital is governed by community and LA social services' policy. One initiative relevant here is Continuing Care, which was used by a number of participants in this study.

Continuing care

Continuing Care is an initiative established to support older people once they have returned home (for 6 weeks) and acknowledges the extra support needed on returning from hospital. It is an example of the policy aim to support older people in their maintenance of independence for as long as possible. This project provides older people being discharged from hospital higher levels of support for the initial six weeks, such as borrowing a commode, more frequent visits by care workers during the day/week, and a post hospital discharge care plan to be followed by those formal workers providing support. This service was experienced as responsive to needs in the first instance but some older people found issues with the reduction of support after this date, for example, one individual living in a terraced house who had to return the commode she was using after the six week period of continuing care ended despite it not being her decision that she was ready.

Personalization

This expansion and development of the notion of service-user 'choice' is apparent in the development of the concept 'personalization' (Ferguson 2007) which allows the flexibility of services, leading to increased options of, and opportunities for, choice, access to appropriate and tailored services, as well as encouraging joined-up professional working and so reducing the experience of a fractured service between health and social care. This is achieved through negotiation between formal providers, informal providers and the individual older person, where the older person, informal carers and family are at the centre of this negotiation (DH 2001a, DH 2004b, Procter *et al.* 2005, DH 2006a).

Many problems experienced as a result of the initial introduction of the *NHS and Community Care Act* (1990) were still apparent in the research group, despite:

- the expansion and centrality of service-user 'choice' and consultation in reference to the identification of need
- the structuring and planning of individual support needs and services
- the increase in awareness and initiatives to identify and address issues of ageism
- the participation of service-user groups and local consultation by the PCTs and NHS Hospital Trusts in the planning, structuring and commissioning of services for older people. The unsuccessful discharge experienced by one older person for example, can be seen as a result of both poor planning and poor communication.

An over reliance on informal support, poor service provision (Tappen *et al.* 1995 cited in Waters *et al.* 2001) and a lack of focussed care (Congdon 1990 cited in Waters *et al.* 2001) still leads to problems for older people leaving hospital and

returning to their own homes. Mrs Woodward faced 'disrupted support' as assumptions had been made about the dynamics and abilities of informal support available to her. Furthermore, her care situation went un-assessed and she was not assigned a key worker or social worker to flag up any changes or arising issues that would require a reassessment and change in planning of her support needs. As a result she left her adapted home and became effectively homeless for a number of months. This was potentially damaging to her health and very stressful as she was responsible for the care and support of her dependent adult daughter who has visual and auditory impairment along with learning disabilities. That she and her daughter could find themselves without appropriate accommodation and support highlights the superficial nature of the notion of access to comprehensive and holistic support for those older people leaving hospital.

Policy presents contradictory demands, for example *Fair Access to Care Services* (2002) which defines the eligibility criteria as a means testing mechanism for targeting resources on those who need it most and represents restrictions on the amount of support available conflicts with policy demands for creative practice made in *Independence Well Being and Choice* (DH 2005a, also Holloway and Lymbery 2007) and calls for social workers to encourage the take-up of direct payments (Ellis 2007). A second example is presented by Sourfield (2005) who cites initiatives such as direct payments (DH 1996, 2003a) as contradictory because they give older people the money to employ someone who is not CRB checked and this is at odds with increased concerns about elder abuse (*No Secrets*, DH and HO 2000). Furthermore, not all policies are evidence-based (Glasby 2005) and people still do not have a say (Doherty and Doherty 2005).

5.1.4.3 Practice

A successful discharge plan is based upon an individual's self-defined needs and how they currently manage their needs (Lloyd 2006) but also builds upon how older people manage well-being and health and develop strategies for managing their lives (Powell *et al.* 2007). To provide this type of person-centred and holistic care, it is necessary that the implementation of policy is effective. However, there are a number of issues surrounding the implementation of policy in practice that disrupts policy aims and does not produce the required outcomes.

First, there is the practical problem of implementing policy that comes if there is no indication within policy documents of how this is to be achieved for all of its aims. The implementation of *Delayed Discharges* (DH 1996, 2003b) can be seen as an example of this as putting the policy into practice was compromised by local differences and complicated by the impact of available service provision (Glasby 2003a). Furthermore, although the aim of anti-ageism is implicit in policy discourse there is no explanation of how to do this in daily practice (Roberts *et al.* 2002). A further issue that impacts on the effectiveness of policy implementation in achieving policy aims is the unintended consequences of performance measurement (Holloway and Lymbery 2007), that is, practice reflects the need to complete or comply with central and local governmental targets and is not driven by the immediate needs of individual service users. The agency perspective then still dominates (Tanner 2003, Lymbery 2005).

Secondly, current policy impacts on the working practices of staff. Professionals, for example nurses and social workers (Holloway and Lymbery 2007), agree with the aims of policy that puts the individual as central to the management and

planning of their own care but remain unclear about how to meet these aims in practice (Beresford *et al.* 2007 cited in Holloway and Lymbery 2007: 376).

Furthermore, the standardization of practice and imposition of procedural rules leads to a tension between ethical values and the daily practice context in which professional care workers operate (Lloyd 2006:1172). However, Lymbery (2005) asserts that it *is* possible to practice professional methods in a managerial framework.

The implementation in practice of current policy that structures the care and support for older people managing the changes involved in hospital discharge and the changes experienced once home raises a further professional concern. It represents a potential threat to skills levels amongst practicing professionals by changing their role from a 'do-er' and enactor of care to an 'overseer' and manager of care; this is further exacerbated by a concern with increasing access by providing advice through call centres and NHS Direct (Ferguson 2007), a source of contact not readily available to all those who are receiving support at home.

Deskilling leads to problems associated with the lack of advocacy understanding by those providing formal semi-professional support both in day-to-day relationships in which changes to needs are managed and met through changes to support, and in the identification and referral required to meet larger scale changes that may impact on the structure of the support received once home.

Central to the implementation of policy is the skilled practice of those who support older people through their assessment of needs and in the structuring of the care

plan, and those who provide support with managing changing needs once home from hospital. Effective communication is vital if older people are going to experience person-centred care where they lead both the definition of need and the structuring of support available to ‘co-produce’ an effective and viable care plan/pathway.

Communication within the multidisciplinary team (MDT) is key in effective discharge (Atwal 2002, Bowles *et al.* 2003, Bolch *et al.* 2005, Preen *et al.* 2005). However the *SAP* (DH 2001a, DH 2002a) is proving difficult to implement in practice due to the presence of different professional cultures and work practices within the MDT (Dalley 2000, Brown *et al.* 2003) and the differing time and resource restrictions each professional group faces (Bowles *et al.* 2003). Lack of time (Atwal 2002) and a competition over resources reduces the effectiveness of inter-professional working. The MDT includes, in theory, the individual older person and their carer (as relevant) and this inclusion is essential for communication to be effective (Walker *et al.* 2007).

Central to the dynamic between members of this MDT is the relationship older people have with formal sources of support, and in particular, professional health care and social support workers that work with them to structure a care plan/pathway for their return home. Unless older people have a voice in the planning and management of changes in their support needs, the work done by professionals is ungrounded (Walker *et al.* 2007) and neither necessarily appropriate nor sustainable.

Good relations between staff and service users can improve the access older people have to responsive and personalised support. The way personnel relate to older people can determine how much they participate in the planning of their care and in what way they take part (Gustaffsson 2004); the language and disposition of staff affect how older people construct themselves (Minichello *et al.* 2000). Talk and language are key (Parton 2003) especially if needs are defined, in part, through the language used to discuss it (Sevenhuijsen 1998 cited in Lloyd 2006:1172). However, older people are not given the opportunity to express themselves and staff are not trusting of an older person's competence to manage (Huby *et al.* 2004, Doherty and Doherty 2005).

Communication with older people is skilled work (Lloyd 2006) as it contains a moral dimension and requires the need to be aware of the impact of professional discourses of dependence and rehabilitation on an older person's experience and decision-making. Furthermore, during discharge, older people are making decisions at a difficult time which increases the levels of stress they face during a time when they are recovering from a frightening and complex experience.

Two issues are therefore apparent. First, without specific guidance available on how to implement policy, practice may not produce the intended outcomes nor meet the policy aims. Secondly, personal relationships are central to enabling policy to work in practice. The type and quality of the relationship between the individual and those who provide support (in the widest sense) influences how appropriate is the help to which an older person has access. It may also impact on

the accessibility of some support types and the opportunity for older people to have a say in needs definition and support planning. In other words, successful relationships are central to both the successful implementation of progressive policy that promotes pro-active user involvement as well as central in determining an individual's experience of the hospital discharge process and effectively returning to life afterwards.

5.1.4.4 Approaches to managing change

The most effective support is based on older people's definition of their needs (Lloyd 2006) and builds upon already existing strategies they have developed for meeting these needs (Powell *et al.* 2007). Therefore older people must be at the centre of planning for support arrangements to be most successful. Policy promotes person-centred care, where older people are able to lead the discharge process by defining the needs upon which support planning is structured and have their participation in planning supported by those around them. This was experienced by some in the participant group, who were able to access some aspects of person-centred care, either by calling on help from others or by being supported by their family in the management of changes. However for some certain problems arose that restricted their access to person-centred care, reducing their ability to have their voice heard in planning, which reduces the fit between a personal view of needs and the experiences of receiving support and increases feelings of dependence. The different experiences of managing change were apparent in the research group and these can be seen as a continuum (see Figure 5.2).

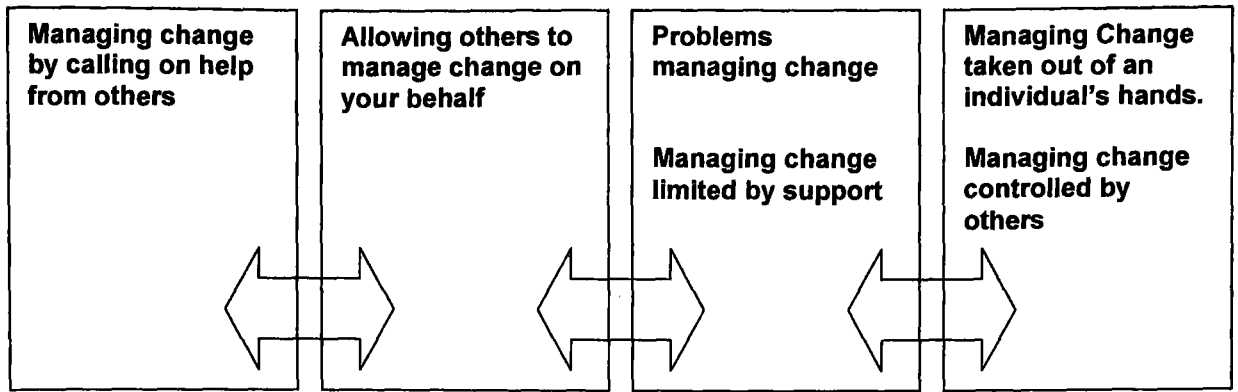


Figure 5.2 Representing the dimensions of Managing Change: a range of approaches to managing changes.

Movement exists across the different approaches to managing change. Those that call on others at certain times or with certain issues may access support from others to manage change in particular circumstances. Those that 'allow others to manage for them' may do this during a time of illness and can reclaim the management of their support as they become more able. Some older people allow others, generally family, to manage daily changes on their behalf. Older people can face barriers where managing change is limited by the support available or the management of change is removed from an individual altogether.

Summary

The categories and the dimensions that organise their properties are summarised below (see Table 5.3).

Categories	Dimensions and Properties
Making Decisions	<p>Voicing needs: 'being able to voice needs', 'negotiating voice', 'voicing opinions made difficult' and 'not voicing an opinion'.</p> <p>Role in decision-making: view as central, view considered, view overruled and view excluded.</p>
Feelings of Independence	<p>Type of care relationship: Empowering or disempowering support. (access/reduced access to appropriate mix of formal and informal care sources and the level of trust, respect and empathy experienced in the relationship with main carer).</p> <p>Type of environment: Enabling or disabling physical environment. (access/reduced access to appropriate housing type and available equipment) (instrumental).</p>
Matters of Concern	<p>Raising concerns: concerns raised by individual, concerns raised by carer and individual and concerns not raised directly.</p> <p>Addressing Concerns: A positive response: information, allowing time to discuss issues, access to appropriate advice when needed (including advocacy and the provision of specialist services such as counselling) and appropriate action. A negative response, not having help addressing issues of concern, the 'wrong' or no action</p>
Managing Change	<p>Approaches to managing change: managing change with the help of others, allowing other to manage change on your behalf, problems managing change and managing change taken out of an individual's hands.</p>

Table 5.3 Table showing categories, dimensions and properties

5.2 Links between categories

Having defined the emerging dimensions that differentiate each category, it is necessary to provide an explanation of how these categories relate to each other.

Developing a theoretical framework is an iterative process, requiring constant referral to experience codes and dimensions arising in the categories and memos and notes made during the research process (Glaser and Strauss 1967, Strauss and

Corbin 1998). Initial models proved either over simplified or over-complicated.

An example of this stage of mapping appears below:

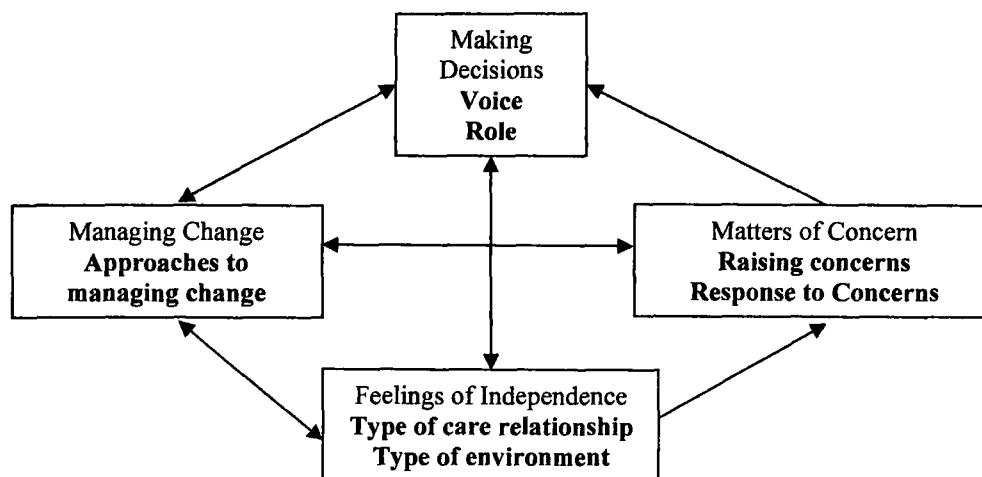


Figure 5.4 Diagram showing an initial model of the relationship between the categories

All the categories are inter-related. An ability to voice an opinion in the definition of personal needs and have that opinion heard and included in decision-making results in a 'good fit' between needs and support and increases feelings of independence. This in turn reflects and results in access to both empowering care relations and an enabling physical environment, However, for many people living in an enabling physical environment and within empowering care relations involves the use of capital, either in terms of money, one participant was able to pay for the care she felt she needed, or in terms of access to informal networks that provided the flexibility to meet these needs. This was a reciprocal relationship, as access to responsive support requires access to empathetic, trustful and therefore empowering relationships with those providing support, and provides an opportunity, if the individual lacks the skills themselves, for their opinion to be voiced on their behalf, in a context where this opinion is heard and considered during decision-making.

Both these categories are related to Managing Change, as differing experiences of decision-making and different feelings of independence result in varying experiences of coping with change. Matters of Concern takes a less central but nevertheless vital role in the process as it offers some feedback between making decisions and feelings of independence as the ability to raise concerns and having these concerns addressed is related to the ability to voice needs and have those views considered, a process central to empowering support.

Further diagrams were developed and recorded in the research diary. As data collection and analysis progressed, the relationships between the emerging categories became increasingly more complex due to the variety of hospital discharge experiences, which is a fluid, contingent and highly individualised process. Using a diagram served to obscure rather than illuminate the relationships between the categories. Managing Change is therefore more clearly described using tables (see tables 5.6 and 5.7, Section 5.3.1.1 The Model). As a core category began to emerge the analysis moved into the final stage.

5.3 The Core Category: Managing Change

The final phase of analysis is achieved through theoretical coding (Glaser and Strauss 1967, Glaser 1978), which is the process of identifying the central social process that defines or describes the phenomena under study (Glaser 1978). The main function of this is to identify an emerging ‘core category’ and relate the other categories to it (Strauss and Corbin 1990).

The core category is explained in terms of the relationships between the categories. The core category that emerged during the analysis is Managing Change, the dimension of this category, how change is managed, contained properties that linked with other categories and linked other categories. The different approaches to managing change are structured by the categories that constitute the core category. The concepts central to the model can be expressed on a table (see Table 5.5 below):

Core category: Managing Change			
Categories	Making Decisions	Feelings of Independence	Matters of Concern
Dimensions	Voicing needs	Type of care relations	Raising concerns
	Role in decision-making	Type of physical environment	Addressing concerns

Table 5.5 Showing a summary of the categories and dimensions of the core category Managing Change

The properties of Managing Change will be explored and a model presented that shows how the categories are related to each other and the core category.

5.3.1 The Experiences Model

The first level analysis of the interview data and memos collected in the research diary, open coding, led to the development of experience codes organised by four emerging categories and their dimensions. Continued analysis clarified these dimensions in the light of relevant literature searches of both research and policy, allowing a fuller definition of the categories. A consideration of the links between the categories led to a dynamic model that saw all the categories related to each other across a complicated net of inter-relationships. Central to this is the category Managing Change, which therefore becomes the core category as it is related to all

other categories, it occurs frequently in the data, it accounts for variation in the pattern of behaviour (Glaser 1978) and describes the emerging social process of how older people manage changes as they move from hospital to home (Glaser 1978, Strauss 1987, Glaser and Holton 2004:18). (How well Managing Change as a category meets the definition of a core category is discussed in Chapter Six).

The changes that occur as older people leave hospital and return home have to be managed. This is achieved in a number of ways, an individual may manage the process themselves, calling on others in certain circumstances or in relation to certain aspects of their support; an older person may allow others to represent them and manage changes on their behalf. Other older people experienced problems with certain aspects of their support and in these ways, their 'work' to manage change had been made more difficult and other older people found that managing change was taken out of their control altogether.

How successfully change is managed, links with the categories of Making Decisions, Feelings of Independence and Matters of Concern. Successful management of change requires that an older person's view of their needs is identified, either through their own ability to voice their opinions or through empathetic negotiation with those that provide their support. These identified needs must then have a central role in the planning of support. As an ideal older people would take an active role in decision-making themselves or be represented by others in this process. Both these aspects will improve the chances of fit between needs as they are lived by the individual and the support that is available to them.

The support resources that are available to manage change are personnel support, a mix between formal and informal carers, and instrumental support, a mix between adapted/purpose-built housing and accessible equipment. For change to be managed successfully, individuals must have access to a mix of carer types that provides them with empowering care relationships. Relationships between older people and their carers must be empowering and therefore respectful, trusting and empathetic. In this context older people are able to raise concerns, negotiate privacy and access to others and take part in the on-going decision-making that shapes their daily experiences.

A third aspect is responsiveness, as successful management must be flexible to continued and on-going changes in an individual's needs. If change is managed well older people have the type of control they want over their situation and they feel that the support they have access to adequately meets their needs and is responsive to continued changes. Timely access to appropriate housing and equipment leads to an enabling physical environment that is essential for older people to cope with changing personal needs and which promotes feelings of independence, building older people's confidence to take part in the management of their care.

Being able to raise matters of concern reflects the ability to voice opinions about care and care arrangements, and therefore has links with Making Decisions and access to empowering care. Having these issues responded to reflects voicing needs as central in decision-making and the responsive management of changes

Although older people in this group reported being largely satisfied with the support they received, some reported experiences highlighting the barriers older people face in the management of changes while returning from hospital to their everyday lives.

5.3.1.1 Barriers

Certain barriers were evident in Making Decisions, Feelings of Independence and Matters of Concern that made the management of change problematic.

Making Decisions

Three barriers were identified in relation to the category Making Decisions that represent the inter-related nature of the two defining dimensions, 'voicing needs' and 'role in decision-making'. Problems arise when needs are not self-defined and care is not needs-led; that is when changing needs are not central to on-going planning and when an individual's opinion is not considered.

Needs not self-defined; Care not needs-led

Problems of communication with formal staff made organising the return home difficult for some, for example liaising with formal semi-professionals (the warden), pinning down an exact discharge date and being included by doctors when organising support for the return to home life. Communication during assessment, planning and implementation is crucial (Bolch *et al.* 2005) and should include the individual and all those who provide support as comprehensively as possible (Atwal 2002). It should ideally be based on individually self-defined need (Pearson *et al.* 2004) if hospital discharge is to be successful (Bull 2000, Bowles *et al.* 2003). Planning should be inclusive of individuals and their carers as well as the relevant professional and formal semi-professional workers through the multidisciplinary team (Preen *et al.* 2005) and the single assessment process

(Glover 2005). This was hampered in some cases by poor communication with the medical team both in relation to individual older people and between professional, formal semi-professional support workers and informal support sources.

Changing needs not central to on-going planning

Problems with intrusive assessments reflect a situation where an individual was not able to put their view point, where the assessment was carried out following a professional agenda (see Section 4.11.1.3 Reviewing: *overstepping the mark*). In addition, problems such as an obstructive warden can impact on the opportunity to identify needs and define and implement the means to meet them, central to the ethos of person-centred care that is a stated policy aim (DH 2001a). Furthermore, the need to adapt the support that was provided shows that an individual's definition of needs is not always heard in the planning of support.

Opinion not considered

Feeling excluded from the decision-making process can lead to support provision that does not meet the needs of the individual. If an individual is unable to voice their needs, they should have access to support to identify those needs. This was not the experience of one of the participants, who was not included in decisions surrounding his discharge home. In fact, arrangements were made that went against his expressed opinion.

Older people's views may be stated but not considered in decision-making.

Although decisions surrounding risk are complex, older people should be included in these or, at the least, have the situation and the decision made explained to them in an accessible manner. Not including older people, reflects a missed opportunity, not only to put them in an empowered position in relation to decision-making

about the care they receive but also to provide older people with the chance to develop the skills that would best enable them to be pro-active in the future.

Barriers to 'voicing needs' can be summarised as a lack of ability to put forward views or identify needs, and a lack of support to define needs through negotiation when this occurs. Not having access to a pro-active role in decision-making can result in not being included or consulted in decision-making.

Feelings of Independence

The category Feelings of Independence is defined by the dimensions: 'type of care relationships' and 'type of environment'. Three barriers were identified in relation to this category: disempowering care relations, problems accessing instrumental support and a disabling physical environment.

Disempowering care relations

Mrs Branson's experience of the warden in her housing complex represents a situation where the warden was using the power dynamic in the relationship to reduce the help Mrs Branson is able to ask for, as Mrs Branson felt that to ask for help could potentially lead to sanctions. This negative use of power resulted in a relationship that did not support Mrs Branson's feelings of independence and a situation that did not allow her the opportunity to discuss changing needs or provide an atmosphere where help could be asked for.

Mr Charles' concern about the unsatisfactory mix between formal and informal support he received continued reflecting the fact that on-going problems can remain unaddressed which reflects a reduced responsiveness of the care an older

person experiences. Mrs Selby's changing situation was not monitored by formal sources so that appropriate help could not be offered when needed.

Problems accessing instrumental support

Not all older people were able to access the instrumental support they needed.

Despite strong family support Mrs Woodward did not have access to timely advice about her accommodation options which resulted in her living in crowded surroundings that limited her ability to remain independent. Having strong family networks did not provide Mrs Woodward with the type of instrumental support that was appropriate to her needs. Economic capital however would have made the process of securing Mrs Woodward an 'enabling physical environment' quicker.

Disabling physical environment

A disabling physical environment resulted in feelings of restricted independence in hospital. Problems such as not being able to use strategies to maintain independence that are available at home due to the limitations of sharing the ward environment, compounded by the problems that arose due to the layout of the ward making it harder to manage continence and problems negotiating access to the appropriate equipment to have a bath for example.

Living in a 'disabling physical environment' leads to a reduced ability to maintain independence. This was Mrs Woodward's experience as she lived in her daughter's home awaiting adaptations to provide her with a downstairs bathroom and shower. As a result of the limitations of the environment, Mrs Woodward was not being able to go to the toilet without help; having to use a commode in a cramped area that was also the bedroom she shared with her daughter Tess, limited her ability to manage her needs herself and threatened her dignity. The

response from the Local Authority was not timely, and reflected agency-level issues rather than individual needs. The wait represents a time of reduced independence and the threat of feelings of dependence.

Matters of Concern

The barriers to managing change that are related to the category Matters of Concern are problems raising concerns and concerns not included in on-going planning and reflected the two dimensions defining the category: ‘raising concerns’ and ‘addressing concerns’.

Problems raising concerns

Older people talked about a number of concerns they did not feel able to discuss, such as concerns about immediate practical arrangements, about medication, about not managing once home and financial concerns. One older woman talked about sanctions that she felt might result if she talked about problems she may be having. Other older people were not offered the opportunity to discuss issues such as being concerned about falling, and the restrictions this concern represented [see Section 4.3.1.2 Identifying concerns: *concerns about falling*] and the impact their need for care had on informal carers that helped them [see Section 4.3.1.2 Identifying concerns: *relying on family*]. This lack of opportunity to raise concerns reduces the effectiveness of this ‘feedback loop’; in other words older people do not get the opportunity to talk about issues that may impact on their support needs. This represents a care-individual relationship that is not empowering and that does not provide an atmosphere within which problems can easily be discussed.

Concerns not included in on-going decision-making.

Those who reported on-going problems and concerns represented a situation where older people’s worries are not being addressed or responded to by providing

a basis for continued refinements of support provision. Continuing concerns about the reliance on family help was an issue raised by older people as they were aware of the pressures their need for support put on their family relationships. Other older people living with pain and living with grief show that issues central to a good quality of life are not always addressed.

5.3.1.2 Facilitators

Facilitators to this process can also be identified.

Making Decisions

Those that had positive experiences of decision-making either had access to cultural and economic capital to organise the support needed during the move home or access to social capital in the form of supportive informal networks (Wenger 1994). This reference to informal helpers in decision-making ranged from asking the opinions of informal carers to allowing them to take an active role in identifying needs and a central role in decision-making support on their behalf. Support provided in the form of professional advice from doctors was also acknowledged as important.

The advantage of having support that has been planned in relation to needs as an individual sees them is evident amongst those who experienced a smooth transition from hospital to home. Those without family help managed the transition through accessing empathetic support offered by the ambulance crew or the ability to pay for the help that was required to smooth this move. In addition, they were returning to purpose-built accommodation that made the first few days home a lot easier.

Once home older people with positive experiences of decision-making either had the money and cultural awareness to be pro-active in on-going decision-making or flexible family support that provided help with decision-making where this was asked for. Organising the home help was one example of how an older woman took back some control over decision-making once she felt well despite the perceived threat of being labelled a 'trouble-maker'.

Feelings of Independence

Feelings of independence are enhanced by access to the appropriate mix of personnel support sources and access to trusting, empathetic and respectful relationships that are essential for empowering care. For the majority this was achieved through access to good family relationships and the ability to buy in the support needed. Having someone to call on in an emergency was an important issue for those who returned to their own homes and in this respect formal semi-professional helpers (such as the warden) could provide some much needed reassurance

Those who experienced enabling physical environments when they returned home generally already had these arranged. Some were offered changes to their instrumental support, in terms of new equipment organised by family members.

Matters of Concern

Although no one referred directly to concerns that *had* been addressed, one participant described herself as 'not anxious... but eager' and this may reflect the access she had to an enabling physical environment and a care relationship in which she felt she could raise concerns if this was necessary.

5.3.1.3 The Model

Managing Change can be expressed on a table to show how the dimensions and properties of each category inter-relates with the core category (see Table 5.6). In addition the barriers and facilitators identified can be summarised (see Table 5.7).

Managing Change		
Dimensions	Properties	
Making Decisions		
Voicing needs	Needs voiced Being able to voice needs Negotiating voice	Problems voicing needs Voicing needs made difficult Not voicing an opinion
Role in decision-making	View included View as central View considered	View not included View overruled View excluded
Feelings of Independence		
Type of care relationship	Empowering support Able to organise own care mix Family ensures appropriate mix Access to trusting, respectful, empathetic and flexible care relationship	Disempowering support Unable to access appropriate mix of support Facing problems with care relationship
Type of physical environment	Enabling physical environment Access to appropriate housing type Access to appropriate equipment when needed	Disabling physical environment Reduced access to appropriate housing type Reduced access to appropriate equipment when needed
Matters of Concern		
Raising concerns	Able to raise concerns Concerns raised by individual and/or carer	Unable to raise concerns Concerns not raised No opportunity to raise concerns
Addressing concerns	A positive response Allowing time to discuss issues Access to appropriate advice when needed Appropriate action.	A negative response No opportunity to address concerns Not having help to address issues of concern The 'wrong' or no action

Table 5.6 Showing the dimensions and properties of the core category Managing Change

Dimensions	Facilitators	Barriers
Voicing needs	Inclusive decision-making Economic power Supportive family Appropriate professional advice	Needs not self-defined; Care not needs-led Poor communication between older person and helpers
Role in decision-making	Smooth transition Support that has been planned in relation to needs Once home Money and cultural awareness to be pro-active in on-going decision-making Flexible family support	Opinion not considered Feeling excluded from the decision-making
Type of care relationships	Appropriate mix of personnel support sources Access to empathetic, trusting and respectful relationships Access to good family relationships	Disempowering care relationships Unsatisfactory mix of carer types Changing needs not central to on-going planning Negative use of power Intrusive assessments Obstructive warden Contact lost with formal professionals
Type of physical environment	Ability to buy in the support needed New equipment organised by family members Having someone to call on in a crisis. Support from formal semi-professional helpers	Problems accessing instrumental support Lack of timely housing advice Lack of money Disabling physical environment In hospital: limitations of sharing the limitations of ward layout problems negotiating access to the appropriate equipment Once home: waiting for adaptations inappropriate equipment
Raising concerns	Supportive family relations	Problems raising concerns Threat of perceived sanctions Not offered the opportunity Concerns not included in on-going planning No support addressing continuing issues
Response to Concerns	Responsive family action	No access to formal advocacy No access to counselling,

Table 5.7 Showing the facilitators and barriers to Managing Change

5.3.2 Discussion

Successful management of change requires access to ‘voicing needs’. An older person’s opinion must be identified, either through their own ability to acknowledge and understand their changing needs, and/or through a process of negotiation. The role of an individual’s view in decision-making is also important, as they can be central or increasingly more peripheral to this process. When an older person’s view is central to the planning of support the arising arrangements will better meet their needs as they see them.

Successful management of change relies secondly on the relations of care. Older people must feel happy with the mix between formal and informal care, as different sources of support were experienced as appropriate by different individuals. The relationships of care between older people and those that support them are central to the management of change. This is better achieved by individual’s who are in relationships that are respectful, trusting and empathetic. Relationships that contain these elements are more flexible and responsive to changes in needs and in addition exhibit collaborative power relations. Empowering care is essential in building confidence and skills to voice opinions and raise concerns.

Successful management of change also requires adaptations to the physical environment in which older people live so they are able to maintain feelings of independence. This includes living in purpose-built housing or adaptations being made to existing housing, as well as, access to the equipment required to maintain independence and meet needs as the individual saw them. Older people living in

an enabling physical environment feel more independent and are better able to contribute to on-going decision-making.

Although not as central as the above, issues of raising concerns and having these addressed represent important aspects of the successful management of change. Listening to the concerns of older people is important in three main ways: it can highlight latent problems and allow for a preventative and timely approach; it can help older people come to terms with changes they face; and it can provide an important emotional outlet that reduces the potential of ill health. Being able to raise concerns mirrors issues of 'voicing needs' in decision-making and issues of an empowering care relationship in Feelings of Independence.

Decision-making is central to this process, as the type of decision-making available to an individual can facilitate or restrict the amount of say an older person has in the way the needs they have (as they see it) are met; this impacts on levels of independence discussed by older people. In addition, matters of concern offers a feed back loop, feeling able to discuss concerns reflects access to a context of empowering care. Response to concerns raised is also important. Concerns can highlight issues that are latent / sinister developing and can offer the chance to provide preventative measures. Actively addressing concerns can reduce the potential for further ill health in a second way; allowing older people to express concerns reduces levels of anxiety, which if allowed to remain high can impact on mental and physical health.

Individual experiences exist within a wider context that shapes and impacts on the genuine choices available to older people. There has been a paradigm shift over recent years, a move away from an emphasis of control and management of elderly care to the empowerment of the older person, both within care planning and the day-to-day experience of support (Dawes *et al.* 2005).

This can be seen in, and maybe results from, an increasing awareness of wider political and cultural discrimination and concerns with tackling ageism. These issues also arise in policy which seeks to promote individual autonomy, placing older people at the centre of organising support through the introduction of a person-centred approach as a mechanism for achieving the ‘best fit’ between needs and support.

Taking part in Person-centred care

The person-centred approach apparent within policy and good ethical practice contains a concept of decision-making that is collaborative, participative and negotiated. The needs of the individual must be central to support planning in order to achieve provision that is needs-led not resource-led and therefore more likely to meet older people’s needs (Lloyd 2006, Tanner2007)

In addition, the needs that structure provision are ideally self-defined, avoiding problems of the imposition of the professional view through assessment and assignment of support that follows professional concerns. Where an individual feels unable to make decisions the professional role requires the provision of accessible and full information, an opportunity to discuss problems and possible solutions with a nurse/carer who has the relevant ethical and advocacy skills to

provide supportive needs identification through negotiation and by ‘being with’ the older person (McCormack 2001). This inclusive approach may be apparent between individuals and specific health and social care professionals on a one-to-one basis or within the more formal collaboration between the multi-disciplinary team, individuals, their carers and family members within the case conference (Moats 2006). The person-centred approach therefore conceives of power relations that are equal or patient –led, with the professional acting as advisor and facilitator (Martin 1998) and carer as ‘executor’ (Collopy 1988) of autonomously made decisions.

Inclusion in decision-making is a central theme on two main levels, firstly at a system/organisation level and secondly at an individual level. At a system/organisation level inclusion is apparent in policy and practice in a number of ways: older people as a service-user group are increasingly invited to take part, through consultation, in the production and organisation of services, inclusion in research commissioning and research projects and the development of inclusive research methodologies and involvement in the associated production of evidence-based policy. This inclusion of older people as a service-user group is also evident in the review and assessment stage where policies and services are evaluated and revised in a reflective approach to improve support provision and increase the accuracy of targeting. At this level, groups such as Help the Aged and Age Concern act as pressure groups, running campaigns and lobbying for changes in policy and policy interpretation and implementation. The improvement of access to a simplified complaints procedure through Patient Liaison Service (PALS) further represents an opportunity for older people to impact on the practice and

implementation of policy as it shapes their particular case. The level of true participation and consultation of older people, as a user group, impacts at an individual level in the experience of the types and standards of support available and accessible.

At an individual level this inclusive paradigm, that promotes user-led, person-centred care and support, reflects consumerist approaches to the provision of health and social care and is evident in two ways. Firstly, the decision-making process surrounding the structuring of support focuses on the self-definition of needs; that is, the definition of need is led by the older person themselves, supported in the definition of their own needs during discharge care packaging. Where individuals feel unable to make these decisions, support is provided through the counselling and advocacy action of either formal or informal carers or a negotiated combination of all spheres of expertise. This includes 'how' things happen as well as 'what' happens; for example, the specific timing of discharge (time/day), who is informed, how discharge is co-ordinated, what services are started, who provides them and how. Decision-making on discharge is seen, in the SAP (DH 2001a), as needs-led, person-centred and managed collaboratively through respectful relationships. The autonomy of individuals to make choices is supported and enabled by the empowering action of carers.

A second level of decision-making is evident in the moment of day-to-day care and is reflected in feelings of independence. Again, dignity and respect are seen as central to good ethical care relations. It is a legal right to exercise self-determination over one's body, and issues of privacy (integrity) are closely linked

to notions of autonomy (Randers and Mattiasson 2004). Care practice codes include notions of the importance of supporting autonomy and concepts of abuse include a lack of choice and autonomy (Katz 1996).

Therefore the ability to behave autonomously within the moment of care is vital in the maintenance of feelings of independence. To be able to have this autonomy recognised and respected is reliant upon external properties, such as the level of empowering action within the care context. In other words being heard and being listened to are conceptually separate. 'Being listened to' may lead to no response, which is disempowering; 'being heard' implies responsive and respectful action as a result, which is empowering. In the first case, the power base remains with the professional/carer: a manipulative power relationship (Martin 1998, Powers 2003). In the second, the relationship is more of equals: either a nutrient or integrative power relationship (Martin 1998, McCormack 2001), or at an extreme in favour of the patient/client/older person: a 'facilitative' relationship (Martin 1998, McCormack 2001).

Person-centred care therefore represents a particular approach to power dynamics within therapeutic relationships that sees decision-making as shared or led by older people in their autonomous action to define their own care needs (self-definition of need) and supported through the empowering action of the environment including the facilitative action of professionals and carers.

The Impact of Capital

The experiences of leaving hospital and going home discussed by older people during the process of discharge, and a return to day-to-day home living are, by their nature, unique and individual, and are underpinned and shaped by the social relations within which receivers and providers of care are involved. The management of social relations necessarily requires relationships that involve and reflect issues of 'power' (Foucault 1977, Bourdieu 1986) and this is true of the social relations that represent the management and provision of support and care for older people (Katz 1996, Powell and Biggs 2003).

Access to person-centred support is mediated through access to social, cultural and economic capital. Levels of social capital an individual has access to can impact on access to advocacy for example. Those who had access to advocacy, and an advocacy experience, were part of social networks as they were supported by family members (Wenger 1994).

Cultural capital can also impact on access older people have to the more empowering experience types. Different cultural understandings can act as barriers to communication. This is apparent in the experience code *disagreeing with doctors* (see Section 4.1.1.1 Planning) and can be seen in the properties of the subcategory *planning made difficult by the actions of others* (see Section 4.1.1.1 Planning), as cultural differences were also apparent in relationships between formal semi-professional support workers and older people.

Economic capital can also impact on older people's experiences. This can be seen in the contrast between the experience code *financial concerns* (see Section

4.3.1.1 Identifying concerns), where the lack of economic capital lead to a source of anxiety for one older woman, and *if I do have any trouble* (see Section 4.1.1.1 Planning) where access to economic capital enabled one older woman to return to self-organisation of care and regain feelings of independence following her return home.

However it is more than simply ‘having’ certain fixed amounts of different types of capital; when and how capital is mobilized and how this is understood by the ‘important actors’ in the relationships that structure care are central forces that structure access to empowering support experiences.

This dynamic ‘capital profile’ has two effects; firstly it can influence the experience type to which an individual has access. The more appropriate type and level of capital mobilised within a professional/care relationship may influence mobility across the experience types.

‘Capital’ has been identified by some as a ‘macro’ property, defining social capital for example, as “features of social structure—such as interpersonal trust and norms of reciprocity and mutual aid—which act as resources for individuals and facilitate collective action” (Berkman and Kawachi 2000: 175), hence differentiating this from social networks and social support evident at the individual level. However the use of the concept in relation to cultural capital as defined by Bourdieu (1986) allows the use of the term to refer to the impact at the individual level of all related social factors.

5.4 Summary

Chapter Five concludes the analysis and presents fuller definition of the categories, considers the links between categories and then identifies the core category, Managing Change, which defines the central social process under consideration (Glaser and Strauss 1967).

The model provides an analysis of care service consumption that allows policy-makers to identify areas where the policy aims of ‘person-centred’ patient-led provision are not being met. Developing a model to view older people’s experiences also provides a method of reviewing and evaluating provision, which can supplement the direct participation of older people in research commissioning, service commissioning and policy evaluation and review.

Providing older people with a voice in the identification of needs and empowering care relationships in the management of changes faced by older people when discharged home from hospital are central to ethics in the care and support of older people (Brown 2003). The prominence of personal autonomy is apparent in law (*Data Protection Act 1998, Human Rights Act 1998*) and policy (DH 2001a, DH 2002a) which express a government commitment to increased choice and holistic person-centred care, where decision-making is shared and negotiated and individual self-defined needs lead the process and structure of care packages, so providing individuals with successful support that meets their needs and promotes feelings of independence.

Ideally, effective management of change requires a positive experience of the dimensions that define Making Decisions, Feelings of Independence and Matters of Concern, with access to all the facilitating factors and facing none of the identified barriers. However, in reality, discharge from hospital is a complex, contingent and a highly individual process and older people face a wide mix of experiences. Our aim as professionals therefore is to enhance the facilitators and address the barriers. Chapter Six will review this model, in relation to research with a focus on discharge from hospital. Issues of rigour will be used to evaluate the quality of the emerging grounded theory model and the limitations and advantages of studying this topic using grounded theory will also be discussed. Finally recommendations and future avenues for research will be suggested.

CHAPTER SIX

CONCLUSION AND RECOMMENDATIONS

As a conclusion to this thesis, Chapter Six presents a discussion of the findings and a review of the quality of the research. A number of arising policy recommendations are made and finally, avenues for further research are suggested.

6.1 Discussion of Findings

The model of Managing Change that emerged during open (substantive) coding in Chapter Four and Chapter Five, and theoretical (selective) coding in Chapter Five, provides an exploration of the relationship between making decisions, feelings of independence and matters of concern and identifies a continuum of approaches to managing change, from managing change oneself to having this control taken away. This section identifies the findings and provides a context for this model by comparing it to other research that focuses on the discharge of older people from hospital to home, a focus that has been continually on the agenda over the past 40 years. A review of how well the research aims were met will be presented. Finally, a discussion of arising and relevant issues will be included.

6.1.1 Identifying Findings

Older people manage change in a range of ways. Some individuals are central to organising their own return home and support once there and call on help from others in relation to certain issues or at certain times. Other older people allow their family to represent them in this process, either temporarily during hospital discharge, or on an on-going basis in relation to the support they receive once home. However some older

people found themselves facing barriers to achieving this ‘work’ in relation to their view of their own needs and still others had control taken from them.

Older people who have positive experiences of moving home have access to a number of facilitating factors (see Table 5.7 Section 5.3.1.3 The Model), such as having the economic power and cultural capital to co-ordinate the move home and support once back and access to appropriate professional advice. For those who called on help from their family in this process, flexible family support was essential. These factors increase the chances of ensuring that support is planned in relation to needs identified by the individual themselves and therefore leads to a smoother transition and more successful support provision once home.

Access to empowering care relationships requires access to the appropriate mix of support sources (as the individual sees it) and relationships which are trusting, respectful and empathetic. The majority of older people in this study achieved this through family relationships. Individuals with access to an enabling environment generally already had this arranged, were able to pay for any further equipment needed or had families who could buy-in for them. In addition, identifying and acting on older people’s concerns was also a process that had family action at the centre.

Those who found managing changes problematic, or, at an extreme, had control of this process taken out of their hands altogether, faced certain barriers. Poor communication, especially with doctors, reduced the effectiveness of ‘work’ older people had invested in identifying their needs and taking a central role in decision-making.

Having to rely on family care was problematic for some and increased the level of disempowerment in the care relationship. Negative use of power was also evident between doctors and their patients and between semi-professional staff and older people and this made managing change more complex. Some older people, once settled in at home, lost contact with formal sources of support. This lack of contact can lead to initially small issues being left unaddressed and potentially developing into larger problems; it reduces the flexibility of an older person's support in the light of changing needs and reduces the access older people have to information, advice and the opportunity to talk issues through.

Many found hospital a difficult environment in which to maintain independence. Having to share, the ward layout and access to equipment were all found to be problematic, but these factors were compounded by staff actions, such as giving laxatives and diuretics to people who had limited mobility and were a long way from a (shared) toilet and not providing clear information on how to 'take turns' with the facilities. Older people had to wait for adaptations to their homes from between a year to eighteen months. This can lead to problems maintaining independence that can become long-term issues and reflects agency- rather than need-led agendas. In addition, this is not a wait that those with the economic capital need endure.

Inappropriate equipment was also a problem reported by older people, such as trolleys that do not fit around furniture and bars for the bath provided for an older woman who was unable to use them. This may be the result of poor assessment or poor planning, but either way does not represent support solutions based on self-defined needs or building on strategies older people already employ.

Raising concerns and having those concerns addressed was problematic for many. Generally older people were given the opportunity to express concerns by family members; very few had access to formal sources of support in this regard leaving those without families at a disadvantage. In addition, those *with* access to supportive and responsive family help would potentially also benefit from formal advice or more specialist help, such as counselling or psychological services.

Issues of choice are central to the experiences of older people; mainly as policy assumes that through person-centred care, older people will be able to take part in the co-production of assessments and planning as well as take a proactive part in the implementation and evaluation of the effectiveness of intervention. However, through the investigation of the experiences of older people in the study group a number of issues are apparent. Older people do not always have the opportunity, or experience, of the empowering context promised them in policy and this is true throughout the categories that arise in this project. Informed decision-making necessitates access to full information, advice and advocacy where required and this is also promised in policy, but not consistently delivered for all those who have weak cultural, social and economic capital.

In order to maintain feelings of independence in a way that is experienced as appropriate by older people, choice is required in relation to when, how, why and which carers are involved in both personal and domestic support, as well as who provides the daily care. Feelings of dependence can arise for those who face problems in their attempts to manage change and those who have this 'work' completely taken out of their hands against their wishes. If choices are limited or not made available to older people, they may be left with support arrangements that are far from satisfactory.

Being able to discuss and reflect upon worries and concerns that may impact on older people's daily experiences is essential for older people to be supported in decision-making and to experience a 'good quality of life'. Counselling and other psychological support are not readily available to those who need it, nor is it clear how to access these services if the need should arise.

Managing Change shows that access to capital (social, cultural and/or economic) can impact on the success, or otherwise, of arrangements made once home. Central, is the point that despite the promise of 'co-production' and advocacy, older people are still not having their points of view routinely considered and acted upon. Despite some older people wanting a say, they do not always have the opportunity to have this heard.

6.1.2 Hospital Discharge: A Literature Review

To provide a context for these findings, a literature review of work focusing on older people's experiences of hospital discharge will be presented. There is a forty year history in the research that focuses on the move older people make as they leave hospital and return home.

6.1.2.1 The Hospital Discharge Process

The hospital discharge process has been a main focus of concern for those supporting older people and providing them with help (Skeet 1970, Age Concern 1975, Waters 1987, Clark *et al.* 1997). This process of planning the return home for older people has developed in relation to a changing political and policy background, however a number of central aims are apparent, that is to: reduce the length of hospital stay, reduce the number of unplanned readmissions, improve the co-ordination of services post-discharge with a focus on planning while in hospital (Shepperd 2004:1) and increase satisfaction (Shiell *et al.* 1993, O'Caithan 1994, Closs *et al.* 1995). Discharge planning

should achieve these aims by reducing the gap between hospital and home (Townsend 1988) and should start as soon as an older person is admitted (DH 2001a, DH 2002a).

Hospital discharge for older people is complex (Neill and Williams 1992, Teirney *et al.* 1993, Morgan Reed and Palmer 1997, Henwood *et al.* 1997, Mountain and Pighills 2003) and processual (DH 1994, 2001s, 2002a, Bull and Roberts 2001). It is politically structured and different for different people (Roberts 2002). Approaches to providing support for older people stated in policy have changed in relation to the dominant political ideology of the time and is reflected in changing policy aims.

Management of Elderly Care

In the 1970s and early 1980s concerns arose in response to the large number of older people in long stay geriatric wards; although they had no medical problems they were unable 'go home' due to a lack of available carer or lack of home. Policy focused on tackling the problem of bed blocking and high readmission rate (failed discharges) in a political environment that demanded a reduction in cost and an increase in efficiency and effectiveness of the type of care available to older people. Older people themselves had little say in the support they received and professionals decided what was best for them (Jewell 1996).

Effective discharge became of increasing interest as a result of research (see Skeet 1970, Tulloch *et al.* 1975) that highlighted the problems faced by older people following hospitalization, however the overriding policy concern continued to be that of finances and reducing the cost of providing care to older people and therefore the pressure imposed on the public purse.

Neill *et al.* (1988) pointed to the deteriorated and demoralised state of some older people who were in long-stay geriatric residential wards, not as a result of medical problems but as a result of their care needs which they were unable to meet. Older people became 'institutionalized' and relatively powerless especially if they did not have a home or family. Sinclair *et al.* (1988) identified low morale amongst those living alone.

Several studies produced in the late 1980s show discharge as both complex and problematic (Tierney *et al.* 1993, Morgan Reed and Palmer 1997). Waters (1987) identified a number of problems, such as poor levels of record keeping and poor communication networks between hospital and community staff. Assessment and discharge planning were not seen as a priority for doctors and nurses and a lack of drug knowledge was apparent amongst patients after discharge. Waters (1987) found, the same as Skeet (1974), that for a successful discharge thorough assessment, accurate record keeping and the provision of information is needed.

Older People as consumers of care

In the late 1980s and the first half of the 1990s policy, such as *Discharge of Patients from hospital* (DH Circular 1989), *NHS and Community Care Act 1990*, *Patient's Charter DH 1992*, *Hospital Discharge Workbook* (DH 1994), addressed these problems through a neo-liberal perspective and aimed to increase choice and consultation, emphasising the importance of informal (free) care and care in the community. Health Authorities and Local Authorities now had a responsibility to establish procedures for hospital discharge however this provision was strongly driven by central strategy as, although it required local organization and documentation, the implementation of policy was centrally monitored (by the NHS Executive, Social Services Directorate) albeit with a joint agenda. This approach was taken ostensibly on

the grounds of increasing choice for older people as care consumers but some critiques see it as a process of increased central control and a money saving exercise.

The National Health Service and Community Care Act 1990 and *Patient's Charter 1992* led to a need for planning on discharge, a requirement to discuss care and support with patients and carers and the necessity for good communication networks. However these changes did not necessarily result in improved support for older people; discharge remained problematic (Wiffin 1995) and many of the problems identified by Waters (1987) were still evident during the 1990s (Jewell 1993, Victor *et al.* 1993, Tierney *et al.* 1993, King and McMillan 1994, Henwood *et al.* 1997).

Strict policy guidelines (*NHS and Community Care Act 1990*) in relation to buying services left a gap between policy aims and older people's needs, for example 21 weeks was the maximum care allowed under the act, but to remain independent in their own homes, older people might require more help than this. In these cases older people were readmitted or referred to the intermediate care team to provide rehabilitation. In addition a shortage of district nurses and rotation of team members in the MDT led to increased problems with communication, when effective communication between MDT members is important (Anthony and Hudson-Barr 1998, West 1999).

Whether Conservative policy was based on research is highly debatable (Henwood *et al.* 1997). For example, interventions have a positive impact when services are planned and implemented by the same body (Nikolaus *et al.* 1999), however, policy structures a discharge process that is planned by one group and implemented by another. This leads to the difficulties associated with problematic hospital discharge such as poor communication between hospital and community (Skeet 1970, Armitage 1990, Curran

et al. 1992, Meara *et al.* 1992 Williams *et al.* 1992) as GPs and community nursing staff are not involved in discharge planning but are involved in the post-discharge support.

Some researchers identified some improvement (McBride 1995 for example) however problems continued. Policy aims focused on the reduction of waiting lists and increasing 'bed turnover' rather than on improving standards of care for older people (Manthorpe *et al.* 1996). Relapse and readmission, for example, are related to carer burden and premature discharge (Willaims and Fitton 1988, Townsend *et al.* 1992 Gautam *et al.* 1996). Planning the return home was not seen as a priority and the development of discharge planning and practice, although evident, was patchy with mass variation (Tierney *et al.* 1993) as a result. The promise of power through consumer choice did not materialize.

Empowering older people

New Labour policy, such as *NHS Plan* (DH 2000a), *NSFOP* (DH 2001a), *SAP* (DH 2002a), aimed to empower older people, within the collaborative relationships necessary to enact person-centred care, but also in a wider social context by reducing ageism in provision, practice and culturally in society as a whole. Concerns with delayed discharge are still evident and a policy of reimbursement (*DH 2003*) was introduced to provide some lever to regulate the relationship between health and social care in relation to spending on older people's care. Despite these aims, problems associated with the discharge process are still apparent.

Hospital discharge arrangements are still acknowledged as patchy, problems exist in relation to consistency across specialties and poor communication and coordination between agencies (Bull and Roberts 2001). Blocked beds are a recurrent concern in all

areas and result in an over-simplified analysis of the hospital discharge process and result in poor joint working between the different providers. The discharge process is increasingly more complex, for example, the pressure to decrease the length of stay and increase the speed of throughput leads to new demands. The pressure on resources has increased since 1993 and local budgetary restraints reduce the speed at which discharge can be accomplished (Henwood *et al.* 1997).

Richards and Coast (2003: 177) suggest that this reflects contradictions between policy and the structure of institutions that provide care as, although a joined-up approach is evident in policy those planning a discharge and those implementing the plan remain as two different groups (a problem identified by Nikolaus *et al.* 1999).

6.1.2.2 Problems at discharge

Problems experienced by patients and their carers during and as a result of hospital discharge have been highlighted in research since the 1970s (Tierney and Closs 1993: 1). Communication has been identified as a problematic area that remains evident despite policy aims to provide joined-up, seamless services that are person-centred.

Bull and Roberts (2001) identify three gaps highlighted by previous research: communication between health and social care workers, between providers and patients and between those that provide formal and those that provide informal care (Bull and Roberts 2001: 572). These barriers to communication reduce the effectiveness of decision-making. A lack of timely information being passed from the hospital to the community team has long been a problem (Tulloch *et al.* 1975, Mageean 1986, Harding 1986, Meara *et al.* 1992, Worth *et al.* 1993, Anderson and Helm 1995, Clark *et al.* 1997, Horne 1998). Poor implementation of the MDT model, including a lack of understanding about the professional role, has also been identified

as a barrier to the effective communication necessary both in making decisions and in the fostering of an empowering care relationship between carers and those who they help (Closs 1997). A further problem highlighted in the research is the lack of notice given by the medical team in relation to the discharge date, where sometimes only a day's notice was given (Bull and Kane 1996).

Communication breakdown between hospital and community workers was apparent in a number of areas in this project and these communication breakdowns had serious implications for older people in these situations. One older person returned home to no services or support for three days and had to be readmitted. Another participant lost contact with formal support staff altogether and this left her effectively homeless (although not roofless) for a short period of time. This potential for breakdown is conceptualized within the core category *Managing Change* in relation to the access older people have to centrality in decision-making, the type of relationship they experience with those (from whatever source) that provide them with support and the access they have to being able to identify and discuss concerns.

Older people were not always asked about home or how they managed once there (Waters 1987, Marks 1994). This restricted communication led to unmet needs (Jewell 1993, Tierney *et al.* 1993, Marks 1994, Bull and Kane 1996, Mistiaen *et al.* 1997). Little information is given to older people about their medication and condition, diets and activities to engage in and avoid. A lack of effective communication was apparent amongst older people in this group as a number discussed concerns about activities they should take part in especially immediately after discharge. Problems with knowledge about medications were also apparent, identified by two older people, one unsure of changes to medications that had not been discussed or explained and another

with the lack of change in medication, where it represented a problem not fully addressed.

Communication of these issues impacts on the reality of the type of decision-making as, without full information, issues of informed on-going consent must be considered in relation to being able to both voice needs and take a central role in decision-making. However it also impacts on feelings of independence as part of a respectful, trusting and empathetic relationship rests on the older person retaining some feelings of control over their management of their own care. Lack of knowledge and understanding can remove these feelings of control, and power then resides with professionals (especially doctors).

This has some resonance with the findings of this project as problems of communication with doctors were apparent surrounding decision-making, where an older person's needs (including the need to have necessary services in place) were not the central concern of all those arranging their discharge. A number of people found that their 'work' to voice their needs and play a central role in the decision-making process was not always acknowledged by doctors and a few found planning the return home compromised by poor communication in relation to their discharge date, a problem identified in past research (Victor and Vetter 1988, Harding and Modell 1989, 1989, Neill and Williams 1992, Roberts 2002).

A range of reoccurring problems during discharge planning that could result in readmission have been identified (Jewell 1993, McWilliam and Sangster 1994, Happ *et al.* 1997), such as lack of carer involvement, insufficient information, lack of preparation for care-giving (Archbold *et al.* 1995, Bull and Kane 1996), little

information about care once home (Archbold *et al.* 1995, Driscoll 2000) and poor advice about the management of diets, medications and the signs of complications. Shepperd (2004) identifies a number of problems still evident despite being identified 20 years ago: inadequate assessment and poor knowledge of the patient's social circumstances, poor organisation (late booking of transport etc) and poor communication between hospital and community.

Lack of communication between health and social care professionals and older people and their carers leads to hospital admission (Marks 1994, Bull and Kane 1996). This is reflected in the model Managing Change as communication breakdown between professionals and the individual and carer is one of the problems identified that threatens the relationship between decision-making and implementing support that suits older people once home.

Conflicts between patients and informal support impacted on levels of participation (Abramson 1990, Dill 1995, Jewell 1996a, Bull and Roberts 2001). Although Roberts (2002) did not identify this as an issue in her study, older people referred her to problems with semi-professional formal staff that were charged with providing them with support. A minority felt an ease of communication with doctors (Roberts 2000) and most did not discuss discharge with them. This is also apparent amongst this participant group and those who disagreed with medical risk decisions for example, had the impact of their 'work' to participate reduced to the extent that decision-making was taken out of their hands.

Ashworth *et al.* (1992) found inequalities exist and states that individuals should have meaningful interactions where they have a right to speak and be heard. Interaction and

comfortable communication is key in an effective partnership between service user and service provider (West and Frankel 1991, Bull 1994, Clark 1996) and essential in effective discharge planning (Jewell 1993, Bull and Roberts 2001).

These issues are reflected in this study, as older people need to be involved in respectful and empathetic relationships to maintain feelings of independence. Feelings of dependence were apparent amongst those who were not able to participate in decision-making and who were left with inappropriate support provision that compromised their feelings of control and the appropriateness of care once home. In addition, this aspect is highlighted in *Managing Change* as it also reflects the ability to discuss concerns and have these concerns acted on appropriately either by addressing the issue or providing full information and reassurance.

Roberts (2002) focuses on participation in the discharge process, finding most felt involved and able to express wishes during discharge planning. Many older people reported feeling consulted in decision-making (Waters 1987, Coulton *et al.* 1989, Fairhurst *et al.* 1996). This has a resonance with the different approaches to *Managing Change* identified in the model amongst those who managed change and called on others in certain circumstances or for certain issues and those that allowed others (mostly family members) to represent them in this process.

Older people felt they lacked the specialist knowledge to match needs to care (Leavey *et al.* 1989, Roberts 2002). All welcomed advice from professionals, for example, and some preferred the service providers to decide. Some expressed views unprompted but even these wanted guidance from professionals and for professionals to have a final say. Some expressed views when prompted (Waterworth and Luker 1990, Roberts

2002) and others accepted the decisions made and preferred professionals to act on their behalf. Roberts (2002) concluded that everyone is different and their wish and ability to join in decision-making at different stages and in different ways should be considered.

Older people should be supported in the building of skills and confidence necessary to identify their own needs (DH 2001a), however planned meetings with professionals are often rushed encounters (Twigg and Atkin 1994). In addition, it is important that older people and their carers are listened to separately (Mountain and Pighills 2003: 150) as stakeholders have different priorities.

Participation in decisions-making does not exist only on one level; different types of participation have been identified in past research. Tokenism (Arstein 1969) is similar to the definitions of participation where older people are one of those consulted during the process (Maxwell and Weaver 1984, Brownlea 1987). If older people are truly participating there are signs that they are active in this process (McEwan *et al.* 1983). Bull *et al.* (2000) found positive outcomes in relation to the use of a partnership approach to the relationship between older people and professionals.

Anthony and Hudson-Barr (1998) state that communication is central to achieving effective discharge for older people from hospital (Bull and Roberts 2001: 571), When older people not involved the plan often has to be revised (Tierney *et al.* 1993), and so involving patients leads to better outcomes (Jewell 1996, Bull *et al.* 2000). Open, honest communication that is continuous and timely is necessary between professionals, and between professionals and older people as well as those who support them at home (Bull and Roberts 2001) as a positive relationship between

decision-makers and older people is necessary for participation (Cahill 1996), however, Bull and Roberts (2001) see paternalism of the hospital staff, an attitude that 'nurse knows best' (Jewell 1996a), as a factor that reduces the involvement of older people in decision-making. The importance of good relationships between older people and those helping them is evident in this study, as empowering care relationships represent an optimum context within which to manage change effectively.

Research has shown that, although some do not wish to be consulted (Beisecker 1988, Jewell 1996b, Roberts 2002), many older people do not feel adequately involved (Jewell 1993, Congdon 1994, Bull and Roberts 2001) and some are subordinate to their family and professionals (Abramson 1988, Jewell 1996a). This was reflected in my model in relation to those who faced problems in their management of changes and those who had control of this process taken out of their hands.

The SAP (DH 2002a) aims to rationalise assessments and provide the context for a joined-up collaborative approach to inter-professional working and recommends that discharge planning and assessment of support needs once home should begin during admission. Accurate assessment of older people's needs is essential. For example, Townsend *et al.*'s (1988) detailed evaluation of interprofessional assessments found that inadequate discharge planning and domiciliary services led to early and unnecessary admission to residential care.

The pre-discharge visit can be seen as a speedy solution to the complex process of older people going home (Neill and Williams 1992). However, home visits are presented as simple when in fact they represent a complex balance between carers' needs and older people's desire to go home (Bore 1994) as well as risk factors and

available services (Mountain and Pighills 2003). Older people's quality of life often has to come second to safety, resources and services (Clark *et al.* 1996: 56).

Respondents with family and friends were in a stronger position to be involved in planning than those without (Roberts 2002: 418). Those who are able to mobilize, communicate effectively, are lucid, continent and had low levels of dependency pre-admission are more likely to experience a successful discharge (Flannigan *et al.* 1995, Mountain and Pighills 2003). This does not reflect the aim of person-centered care but instead reflects the impact of structural forces in the form of agency-led concerns.

Successful discharge requires effective communication between providers (Bull and Roberts 2001) and for both services and funding to be available (Victor *et al.* 2000). Unmet needs, such as a lack of appropriate information in relation to the recovery process and a lack of adequate help with household activities can result in readmission. Over reliance on informal support and lack of (or slow) statutory service provision also reduce the success of hospital discharge (Waters 1987, Victor and Vetter 1988, Jackson 1990, Williams and Fitton 1991).

Post-discharge support is necessary (Naylor *et al.* 1999) as older people report problems in the first week with personal and domestic activities of daily living (Mistiatiæn *et al.* 1997), however many express a need for some help on discharge which they do not receive (Neill and Williams 1993: 4, Mountain and Pighills 2003). Older people do not always accept the support that is provided to them; Mountain and Pighills (2003) suggest that this can be improved if older people and the specialists who support them (for example occupational therapists) have time to get to know each other and build a rapport (Mountain 1998). This parallels the concerns for trusting,

respectful and empathetic relationships identified within the model of Managing Change.

Discharge as a process

Discharge from hospital is processual and differing models of this exist. Generally a holistic point of view is taken, for example Bull and Roberts (2001) refer to a four stage process of hospital discharge: *getting to know the patient, making initial plans for discharge, getting ready to go home and transition*. They identified communication problems that existed at each stage in relation to the three circles of communication and defined impediments to a 'proper discharge' both at a system and communication level. *Hospital Discharge Workbook* (DH 1994) also identifies the discharge home as one part of a process that includes: pre-admission screening, the admission process, preparation for discharge, discharge home, post-discharge care (Mountain and Pighills 2003). I have looked at the discharge process in terms of the interview stages I was able to access, preparing for home, getting home (transition and the first week home) and being home (eight weeks after discharge). In addition, Bull and Roberts (2001) identify the factors that enable and inhibit the success of the discharge process.

Roberts (2002) describes differentiation between approaches to the management of change in her analysis of participation in the discharge process. She refers to different types and definitions of participation that represent different relationships between the service user and service provider. These ideas are mirrored to some extent in the model Managing Change, which identifies the importance of collaborative decision-making where an individual's ability to voice needs, or have their opinion represented is essential to ensure appropriate support once home, increase feelings of independence and develop a relationship of trust where older people can freely identify and discuss their concerns without fear of sanction. Boaden *et al.* (1982) defined participation as

“the right of people to make representations and express their views” that is meaningful reaction will lead to people feeling that their view is considered.

However, despite 40 years of research (Skeet 1974, Waters 1987, Jewell 1993, Victor *et al.* 1993, Tierney *et al.* 1993, King and McMillan 1994, Henwood *et al.* 1997, Shepperd 2004) often highlighting the same problems, policy is still not providing older people with the empowered support they have been promised.

Managing Change as a conceptual framework builds on this research by providing a way to view the process of discharge from the older person’s perspective. It emphasizes the need to see participation in decision-making and feelings of independence as inter-linking concepts, as an individual must feel some control over the way their needs are defined and responded to in order for support arrangements to be developed that foster feelings of independence. In addition, older people’s concerns should be discussed and addressed, through the provision of information, reassurance and/or action. To achieve this balance, older people and their carers need to be engaged in empowering care relationships, both during hospital discharge and in day-to-day support. Developing and maintaining these relationships must be recognised as skilled work. Where these skills do not exist, an older person should have access to support in developing these skills or an advocate to act on their behalf. In addition, access to environments that support independent living is essential, especially at home.

6.1.3 Meeting the Aims

In this project I have explored the experiences older people have of leaving hospital and returning home with a focus on the consumption of and access to support appropriate to meeting their self-defined needs. I aimed to develop an understanding of older people’s experiences during the discharge process, to explore experienced levels

of ‘co-production’ during the planning and implementation of support, to investigate the appropriateness of these plans as seen by older people once home, and to develop a model that allows some comparison between individual experiences and in relation to policy aims.

This exploration was important for a number of reasons. First, there is a growing number of older people in society and as such this represents a growing area of concern for older people and the population in general. Secondly, there has been a change in focus over the last decade and a half, represented in proposals within the *National Health Service and Community Care Act (1990)*, *National Health Service Plan (DH 2000a)*, the resultant *National Service Framework for Older People (DH 2001a)* and *Single Assessment Process (DH 2001a, 2002a)* and subsequent reviews of implementation progress (*Better Health in Old Age DH 2004b*, *A New Ambition for Old Age DH 2006a*, CHAI 2006). This change represents a shift from ‘doing to’ people towards ‘doing with’ people (McCormack 2002), which emphasises the rights and responsibilities of individuals in relation to their health, and champions the need for choice.

To ensure ‘choice’ in managing support there is a need for autonomous, dignified care that places the user view central to the structuring of specific support packages, as well as access to a range of quality services. Concomitant with this is the need for both the participation of older people in the structuring and shaping of discharge support packages specific to their individual needs *and* consultation with older people as a user-group in relation to the commissioning and delivery of health and social care services. However, evaluating levels of participation as an individual and consultation as a user group is problematic in terms of, for example, how this is to be achieved and

how to access the wide range of older people using publicly provided support services as well as those who may benefit from, but have no contact with, health and social care professionals.

Thirdly, exploring experiences faced by older people and comparing these to policy aims provided an opportunity to look more closely at the impact of policy on older people's daily lives. For some individuals and in some situations the gaps between what policy intends and the outcomes of implementing policy are apparent.

Highlighting the areas of concern contributes to both consultation and participation. Gaps evident within categories between policy and practice can highlight areas of focus for future research as well as review of policy. Gaps evident within older people's specific situations can lead to an evaluative review of individual support arrangements and provide an opportunity for future planning, increasing the responsiveness of support services and the appropriateness of support for the individual.

Fourthly, political and social policy debates surrounding the care of older people include: increased concerns with regards to the health and social care divide and lack of 'joined-up' care provision, issues of funding that provide health care as free at the point of delivery and social care support as means tested through the eligibility criteria (*Fair Access to Care Services* DH 2002c), the need to provide fully consultative person-centred care in an atmosphere that is agency- and resource-led, and dominated by the professional view. This leads to the moral debate that focuses on the right to free will and investigates the efficacy of intervention in a lifestyle chosen by the individual. That is, do we 'allow' individuals to choose from a range of options that meet risk assessments pre-designated by professionals and is the apparent alternative to

take a completely ‘hands- off’ approach and allow individuals to live in risky conditions and situations?

6.1.4 Seeing the Gaps

Investigating the gaps between policy aims and the outcomes experienced by service users is of benefit in a number of ways. It provides a view of areas for development and first hand reporting on how policies impact on daily lives so allowing for the development of policy design and implementation as well as the necessary training and professional development of those that provide care. Evident here is a divergence between what is assumed in policy and what actually exists within the experiences of older people receiving home care.

Assumptions are made in policy with regards to practice and skills levels. To implement and practice person-centred care, both in the structuring of support for the return home and the responsiveness to changes in condition, situation and self-defined needs, it is necessary for those working with older people, both formal (professionals and semi-professionals) and informal care workers to have access to training and support to ensure they have the appropriate advocacy and counselling skills necessary to implement policy effectively. Ethical training is essential here, allowing carers to explore their own prejudices and fears, in developing an anti-ageist and respectful approach. Therefore, caring for older people cannot be considered ‘common sense’ work, but instead should be seen as skilled and therefore deserving of recognition, in terms of professional standing and autonomy, appropriate training and pay.

Assumptions are made in policy and practice about family relationships and informal care. For many older people empowering care relationships were accessed through informal support. It was not always the case that ‘informal is best’ as, for some, levels

of empowerment were threatened by having no option but to rely on informal care.

This can lead to increased feelings of dependence and can threaten the health of family relationships.

A long-term view should be established that is not directly affected by changes in government ideology, but provides a firm and logical basis from which policy can be developed and implemented. Devolution of the health and social care services, of the type apparent in the financial world with the establishment of an independent body to manage the Bank of England, would provide a stepping stone to independence and facilitate this long-term approach.

The notion of 'joined-up' provision is not possible while funding remains antagonistic. In policy the aim is to provide a seamless service, however, policies such as reimbursement remain, placing health and social care in competition with each other. Underpinning the approach to health and social care are notions such as the medical view that sees it as possible to define older people's issues as 'medical' and 'other/social'. The cultural division is due to both the historical evolution of services and conflict between differing professional views and is maintained by the economic interests of both the medical (doctors, pharmacists, nurses and associated therapists) and pharmaceutical industries.

Finally, there is a need to constantly review and evaluate individual experiences of support to provide the data necessary to review policy as they can feed into public consultation and supplement information gathered through public meetings, focus groups and surveys, such as those developed for the Dignity in Care Initiative (*Opportunity Age* DWP 2005, *A New Ambition for Old Age* DH 2006a).

6.2 Review of Quality

Two central issues will be addressed, the quality of the arising theory in relation to definitions of fit, work, grab and modifiability and an evaluation of the success of choosing a grounded theory methodology.

6.2.1 Issues of Rigour

Fit

Evaluating a grounded theory in relation to 'fit' is an effective way of establishing 'the levels of validity and truth' of a model (Lomborg and Kirkevold 2003). 'Fit' is a measure of how well the grounded theory expresses the data, that is theoretical categories must arise from the analysis of data and must explain the data (Glaser 1978, 1992), with any existing categories 'earning their way' into the theory (Glaser 1978, 2001). In addition, if a grounded theory is carefully induced from the substantive area its categories and their properties will make sense and be recognisable as expressing the central social process by older people themselves as well as practitioners and researchers in the area (Locke 1996, Glaser 1998). Therefore, to identify the fit of the data to the emerging theory the core category, Managing Change, can be evaluated in relation to certain criteria that define the concept of 'core category' (Glaser 1978: 94-95, Strauss and Corbin 1998:146, Glaser and Holton 2004:18) and the application of the constant comparative method.

Meeting the definition of a core category

To emerge as the 'core category' a category must be central and occur frequently during the analysis (Glaser 1978, Strauss and Corbin 1998). The core category Managing Change occurred within each of the emerging categories as different approaches to decision-making, differing experiences of maintaining independence and differing access to raising concerns and having these addressed all exhibited different

approaches to managing each aspect of change. These ranged from managing changes oneself with help from others, allowing others to act as a representative in this process; facing problems and having these processes taken out of one's hands.

The core category should take more time to saturate (Glaser 1978). It was unclear whether saturation occurred (due in part to the resources available to the project). However, Managing Change was a rich category that initially contained a vast array of experience codes. Many links with other categories became apparent during the process of constant comparison used to identify the dimensions of categories and the links between them. This meets a further criterion (Glaser 1978) that indicates that Managing Change is the core category. In addition, the core category must be able to explain variation in all categories and settings (Strauss and Corbin 1998:146); Managing Change explains some of the variation evident across the experience codes (Glaser 1978, Strauss and Corbin 1998). For example, different approaches to managing change impacts on the type of decision-making available to an individual.

The category Managing Change therefore meets a number of the criteria to identify it as the core category. In addition to this, the 'fit' of a grounded theory depends upon the model being 'grounded' in the experiences of older people through a particular process of data collection and data analysis, the constant comparative method, where the emerging concepts are continually compared to collected data. In this way a model can be developed that explains the process of how change is managed by older people during hospital discharge which can be applied (Glaser 2002) to a variety of situations and people who are moving from hospital to home, and more widely, from one agency to another. That is, through conceptualisation (Glaser 2002) and good application of methodology, a model can be developed that is applicable to other contexts. Older

people manage changes they face during the receipt of support through an integration and iterative inter-relation between the type of decision-making, care relationship and environment to which they have access. This is evident during the discharge process for older people but also during the on-going and daily receipt of care.

The 'fit' of the final model also depends on the quality of application of the constant comparative method during data sampling and data analysis. To further evaluate the 'fit' of the emerging conceptual framework a review of the use of the constant comparative method in this investigation is necessary.

Using the Constant Comparative Method

The constant comparative method requires concurrent data collection and data analysis so that new information can be compared to data already collected (Carpenter Rinaldi 1995, cited in Chiovitti and Piran 2003:429) and in this way, categories and the dimensions defining those categories can emerge from the coding of empirical experiences (Glaser and Strauss 1967, Strauss and Corbin 1990). This method of simultaneous data collection and data analysis requires the use of theoretical sensitivity (Charmaz 2006) where the researcher is alert to emerging codes during the process of coding, and uses these initial codes to both guide subsequent coding at all levels (Strauss 1987, Charmaz 2000:515) and to further data collection through the use of theoretical sampling (Glaser and Strauss 1967). This process comes to an end when emerging categories and their dimensions become saturated (Glaser 1978) and no new categories or dimensions are apparent.

Data collection and data analysis were initially chaotic and difficult to manage. As a new researcher I was unsure about how to identify ideas that were important and those that were not. The first stages of using the constant comparative method involved a

vast amount of information to be recorded and considered. This in itself took a level of organisation which was extremely challenging. A research diary was used to record field notes and ideas about emerging experience codes, and eventually memos. This provided a more organised approach to data analysis. This analysis shaped data collection by identifying questions to be asked of individual older people about their experiences of leaving hospital. In this way, categories that began to emerge during data analysis could be further investigated in subsequent interviews. A number of central aspects to the constant comparison method were therefore evident. It remains unclear whether all categories and dimensions became saturated as resource limitations meant that access to participants was restricted, for example, to a particular time period. In addition, using the constant comparative method effectively requires certain skills, such as the ability to conceptualise (Glaser 2002) and be aware of emerging codes (Charmaz 2000); these skills can only develop with experience.

Charmaz (2000: 515) identified five aspects of the constant comparative method. The first, involves making comparisons between different people in relation to views, situations, actions, accounts and experiences. This project compares experiences and views of individuals in different situations who are all moving home from hospital. The second aspect identified by Charmaz is a comparison of data from the same individuals with themselves at different points in time (2000: 515). Here, this was made possible by the structure of the interview series, so that issues and codes that arose in one interview could be explored again in subsequent interviews with the same individual. In addition the structure of the interview series and the use of theoretical sampling made comparing incident with incident (the fourth aspect) possible. Older people's experiences were explored for emerging codes and these were used to inform

questions asked and subjects addressed in subsequent interviews. Theoretical memos also allowed for a more conceptual analysis during this type of comparison.

Comparing new data to categories that emerged during the analysis of previous data, the fifth aspect identified by Charmaz (2000: 515), provides a fuller definition of each category as dimensions that organise the experience codes become apparent. This was evident in the data collection and analysis here. A problem may arise, again in relation to the level of saturation apparent for each category and the dimensions that define them. Continued data collection and analysis would identify whether saturation has been achieved.

The final aspect of the constant comparative method is the process of comparing category to category. Selective (theoretical) coding identified a number of links between the categories. From this process the core category Managing Change emerged.

Certain pitfalls, which can compromise the standard of fit, are to be avoided, such as conceptual description (Glaser 2002: 21), conceptual foppery and conceptual vagary (Glaser 2002: 24). Conceptual description refers to the danger of ‘incident tripping’ (Glaser 2002:22) where one concept becomes central to the data collection and data analysis too early and subsequent data is coded in relation to this; or one incident, which is a conjecture rather than a pattern, is used to explain a range of issues (Glaser 2002:21). This leads to the forcing of a theory rather than allowing it to emerge.

Conceptual foppery at the opposite end of the spectrum, refers to the hazard of conceptualising ‘every incident in sight’ (Glaser 2002: 24), leading to a diffuse

analysis that lacks a central analytical thread. Conceptual vagary refers to the situation where concepts emerge initially but following further analysis lose detail and become vague (Glaser 2002: 25). These issues are avoided if the properties that define the categories are carefully generated and conceptually saturated. However, this requires a skilled hand on the part of the researcher that was not available as I was learning about grounded theory and the analyses upon which it relies during this project. Problems understanding how the process of constant comparison is implemented at the beginning of the project may have led to conceptual description in some aspects of the analysis as I was keen to feel progress was being made.

Conceptual foppery was also a potential problem as a result of my learning about the process as I 'went along' and there have been times during the work on this thesis, again through a need to feel productive, where a wide range of categories emerged. In an attempt to be parsimonious and follow a central analytical thread a number of these categories were subsumed within other categories, however this could have been more extensive as, for example, a wide range of experience codes remain.

These issues can reduce the 'groundedness' of the emerging theory and threaten the 'fit' of the conceptual framework to the data and to the central social process the model seeks to explain. The conceptual framework presented here does show 'fit' and I feel is truthful to the data as the core category, Managing Change, describes the process by which decision-making, the care relationship and the living environment inter-relate, impact on and are shaped by the way older people manage the changes they face in their daily lives. In addition, this model reflects my experiences of the interviews with the older people I met during my fieldwork and relates to the process I have experienced as a staff nurse working on the DME.

Although 'fit' is the central concept in the evaluation of quality, a grounded theory must also have relevance and explanatory power (Glaser and Holton 2004:18) and be adaptable to new data; that is, in addition to 'fit' a grounded theory must have work, grab and modifiability.

Work

If a grounded theory works it will explain the major variations of behaviour in the area, with respect to the processing of the main concerns of the subjects. Therefore a grounded theory must be able to explain what happens in the data, predict what will happen, and interpret what is happening in the area studied (Locke 1996). Workability is related to how well a theory accounts for the way in which participants solve their main concern (Glaser, 1992, 1998).

The use of the constant comparative method, that is the simultaneous collection and analysis of data, provides a way to ensure that theoretical constructs arise directly from the data (Glaser and Strauss 1967, Strauss and Corbin 1998). This is achieved as the arising concepts are continuously 'tested' against subsequent data and emerging analyses, and that the developing theory reflects the empirical reality.

The model presented here does explain how older people manage the changes they face on discharge from hospital and what is happening in the data. It is less clear whether the model can predict what will happen. However, as a grounded theory model contains the property of modifiability, differences in future data can help to develop the model further (see below).

Grab

The third criterion concerns relevance (Glaser 2002). A theory is relevant and has good grab when it allows an explanation of the core problems and processes in the area to

emerge (Locke 1996). A grounded theory with 'good grab' "can instantly sensitise people, rightly or wrongly, to seeing a pattern in an event or happening that makes them feel they understand with 'know how'" (Glaser 2002: 16).

To ascertain whether a model has 'grab' one approach is to discuss the model with older people and their carers who live and work within this context (Coyle 1999).

Although I have been unable to return to my participant group (a problem highlighted by Coyle (1999: 104) in relation to the methodology of grounded theory) I have discussed the model, in particular the facilitators and barriers it identifies, with one older woman and her carer. Both found some resonance with the categories as they were described and problems such as relying on family for care and problems communicating with doctors. However, Glaser (2002:5) reminds us that a grounded theory does not represent the 'voice' of participants, as a grounded theory aims to provide a conceptual model of what is happening in a certain field that participants might not be aware of or understand.

Grab can be assured if the concepts are not forced but emerge from the data through constant comparison (Glaser 1978) and that saturation of concepts (Strauss and Corbin 1998) is achieved through this process using theoretical sensitivity. Therefore a strong understanding of grounded theory methodology and of the process of constant comparison is essential in order that concepts emerge from the data. In this project it was unclear whether saturation was achieved. Constraints in resources such as time, access to participants and researcher skills may have made saturation, or awareness that saturation had occurred, reduced and limited.

How much relevance a theory has underpins its level of 'fit' as the ability to 'ring true' (Glaser 2002: 16) reflects how well a conceptual model explains the process under study. Therefore if a conceptual framework has 'fit' it must also have 'grab'.

Modifiability

The fourth criterion is modifiability; the theory should be readily modifiable when new data present variations in emergent properties and categories. A substantive grounded theory has only partial closure because new ideas and more data can modify the theory. Modifiability is therefore an ever-ongoing process, and all grounded theories have potential for further development (Glaser 1978).

6.2.2 Using Grounded Theory: Choice of Methodology

Exploring older people's experiences using grounded theory is of great value here. First, it allows an inductive investigation into issues seen as pertinent to older people. Secondly, it allows for older people to express their experiences in their own words, providing a basis from which to develop future research projects. Thirdly, it allows an exposure of the gaps between individual experiences and the policy and practice guidelines that seek to structure them. Fourthly, qualitative grounded theory also allows for the development of a (tentative) mid-range, substantive model (Glaser 1978) that expresses and/or explains older people's experiences of this phenomena (Chiovitti and Piran 2003: 433). Fifthly, it provides an approach that will allow the use of individual experiences to evaluate central policy, local policy, the process of implementation and review of individual cases. Finally, by providing a temporal dimension in the review of the discharge process individual careers or journeys home can be evaluated, reflecting a joined-up approach to the evaluation of support provision, its responsiveness to changes in self-defined needs and the appropriateness of support packages and support options.

The use of grounded theory therefore has certain strengths in investigating this subject and this type of model building can highlight the need for future research, however, limitations are also evident. Only a small sample of individuals can be used in this in-depth approach and it provides a final analysis in which the feeling for the older person's experience as a whole may be lost, therefore reducing the impact of the holistic approach.

Grounded theory provides a method of interpreting qualitative data and structuring it in the production of a model. This also can reduce the holism of an individual's experience that may be captured through other approaches such as the biographical approach (McCormack 2001), where an individual expresses their experiences through narrative and storytelling. However, despite this, models produced through inductive analysis can provide an overview and a schema within which narrative studies can be interpreted and explored.

6.3 Implications for Practice

From this review of individual experiences and the associated analysis several recommendations can be suggested. A greater emphasis is needed on discussing the concerns and worries faced by older people on their return home. This also exposes a lack of access to appropriately skilled advocacy and counselling necessary for older people to manage their own needs through decisional autonomy and the freedom to delegate executional autonomy (Collopy 1988).

Associated with this is, the need to provide older people with a fully accessible complaints procedure that may be improved with better information about access to it

and possibly a ward presence of co-ordinators of advocacy, counselling and complaints.

Older people need greater support to maintain social contact, as this is necessary for a 'good quality of life', allows opportunities to discuss concerns and worries with those in similar situations and therefore provides access to different coping and managing strategies. Social interaction is also necessary to the maintenance of mental and therefore physical health.

Full consultation and consideration of older people's views and current ways of managing should always be considered if the care package is to be effective, satisfactory to the individual and tailored to their needs. Although this aim exists in policy, it is not always reflected in the experiences discussed by older people.

Clearer communication is needed between the medical team and patients and between and within professional groups. The importance of an older person's view must be understood by all the members of the MDT, including the doctors as well as older people themselves.

These issues, evident at an individual level, also have implications for practice. To support policy requirements for the centrality of person-centred care and the autonomy expected for older people, appropriate training is necessary for all those who provide care, not just professionals, but all formal and informal carers. Support of older people must be seen as the skilled work it is and have the appropriate status as a discipline. This is only possible through a cultural shift, which would be encouraged by reflective practice for *all* levels of staff.

A 'one-stop-shop' that provides support for a wide range of issues would encourage an increase in user involvement in the appropriate evaluation of their support. This is in part supplied through the new structure of the PCTs, and schemes such as Sure Start, or Healthy Living Units (Age Concern). However, not all people are aware of these services, and contacting health workers for medical issues and social services for social issues, still leads to confusions and omissions. A named support worker could maintain contact with older people in their own homes and provide advice and access to support for those experiencing changing needs.

Currently, direct payments cannot be made to carers who live with those for whom they care; the use of money payments to pay for family care would reduce the tendency for formal support co-ordinators to take family relationships for granted. In addition regular inspection, review and evaluation of provision for those who receive care at home may provide support for both older people and their carers

At a structural level, a critical review of the relationship between pharmaceutical companies and individual doctors, nurses and other professional workers must be undertaken to reduce the potential for inappropriate use of medication and treatments. In addition, the use and regulation of not-for-profit domiciliary care services is essential if the care older people receive is not to be tightly restricted by the working pressures of formal, semi-professional support workers.

6.4 Further research

6.3.1 Problems with research method

There are a number of ways this project can be enhanced. First, older people can be included in the design of the project, the choice of subject area, or the process by

which the research was carried out. Secondly, the sample size is small and although there was a series of three interviews with each participant, triangulation with other methods of data gathering such as focus groups or questionnaire, would give the findings greater efficacy.

This project was carried out in one north eastern city; a broader understanding would be gained if more diverse locations were used and compared, for example carrying out similar interviews with older people returning home in the rural areas.

6.3.2 Strengths of research

Despite these problems, the research method also shows two main strengths. First, the inductive method looked at older people's experiences as they talked about them, and attempted to avoid imposing external categories but instead, external categories apparent in policy were matched to categories emerging from older people themselves.

Secondly, a model was produced that can be to identify the barriers and facilitating factors associated with achieving a successful discharge from hospital to home. This model could allow the inclusion of qualitative data into an environment with a tradition best understanding of quantitative research.

Thirdly, as a substantive, mid-range conceptual framework, the Experiences Model is applicable to other situations and can be used to evaluate person-centered policy beyond the investigation of those older people returning home from hospital care. It can be adapted, for example, to understand the processes of change faced by older people living in their own homes as they manage the changes apparent in day-to-day life. Managing change is a process that any group leaving hospital and returning home goes through, for example the parents/ main carers of children discharged to 'hospital

at home'. As it contains within it concepts of collaborative decision-making and levels of access to empowering professional/service user relationships the model can be adapted to evaluate any policy that incorporates, or is based on, notions of 'person-centred care' or indeed 'service user-centred' support. This approach is evident, and therefore the model is adaptable to, a range of areas, such as family social work and the relationship between children/ the family and the social workers supporting them, people working with and supporting young people, substance abusers and disabled adults, including those with learning disabilities.

6.3.3 Future areas for research

Future research may focus, firstly, on developing fuller definitions of autonomy and empowerment; specifically feelings of autonomy and empowerment within the main categories raised here. Secondly, further work may develop a deeper view by including professional understandings of individual's needs to contrast with older people's direct experiences. This could be expanded to include informal and formal semi-professional carer understandings of individual's needs. Thirdly, a repeat investigation into older people's experiences of autonomy and empowerment and a review of forthcoming policy could be compared with this project to identify areas that are improving and areas that are not.

Being older is something we will all experience if we are lucky, and as age expectancy rises, we are going to spend a larger percentage of our lives being old. We owe it to ourselves to make old age as positive and exciting as possible. As well as this, we have a promise to fulfil for those who are old now, which is the promise of support from the cradle to the grave.

REFERENCES

- ABRAMSON, J.S. (1988) Participation of elderly patients in discharge planning: is self-determination a reality? *Social Work*, September–October, pp. 448.
- ABRAMSON, J.S. (1990) Enhancing patient participation: clinical strategies in the discharge planning process. *Social Work in Health Care*, 14, pp. 53–71.
- ACHESON, D. (1998) *Independent Inquiry into Inequalities in Health Report*. London: The Stationery Office.
- AGE CONCERN (1975) *Going Home, Report on Continuing Care Project*, Liverpool: Age concern.
- AGE CONCERN (2003) *Free for All? Age Concern Scotland's Report into Free Personal and Nursing Care*, Age Concern, available online at www.ageconcernscotland.org.uk/section/ndetail.asp?s=4&newsid=18&p=4 [Accessed on 24/10/05].
- AGE CONCERN (2007) *Older people in the United Kingdom Key facts and statistics 2007* Available at: http://www.ageconcern.org.uk/AgeConcern/Documents/Key_facts.pdf [Accessed on 11 July 2007].
- AHMED, L.B. and KITSON, A. (1993) Complementary roles of nurse and health care assistant. *Journal of Clinical Nursing*, 2, pp. 287-297.
- AKERLIND, I. and HORNQUIST, J. (1992) Loneliness and alcohol abuse: a review of evidence of an interplay. *Social Science and Medicine*, 34 (4), pp. 405–414.
- ALPASS, F. M. and NEVILLE, S. (2003) Loneliness, health and depression in older males. *Ageing & Mental Health*, 7(3), pp. 212–216.

- ALTMAN, I. (1976) Privacy: a conceptual analysis. *Environmental Behaviour*, 1976 (8), pp. 7-29.
- AMOS, G. (1973) *Care is Rare*. Liverpool: Age Concern.
- ANDREWS, G. J. (2002) Private complimentary medicine and older people service-user and user empowerment. *Ageing and Society*, 22, pp. 343-368.
- ANDERSON, B. (2000) *Doing the Dirty Work? The Global Politics of Domestic Labour*. London: Zed Books.
- ANDERSON, M. A. and HELM, L. B. (1995) Communication between continuing care organizations. *Research in Nursing and Health*, 18(1), pp. 49 – 57.
- ANDREWS, G. J., HOLMES, D, POLAND, B., LEHOUX, P., MILLER, K.-L., PRINGLE, D. and MCGILTON, K. (2005) Airplanes are flying nursing homes': geographies in the concepts and locales of gerontological nursing practice. *Journal of Clinical Nursing*, 14 Supplement S2, pp. 109-120.
- ANTHONY, M.K. and HUDSON-BARR, D.C. (1998) Successful patient discharge. *Journal of Nursing Administration*, 28, pp. 48-55.
- APPLEGATE, M. (1994) Personal privacy and interactional patterns in a nursing home. *Journal of Aging Studies*, 8, pp. 413–33.
- ARBER, S. (1993) The Research Process. In: Gilbert, N. (ed.). *Researching Social Life*. London: Sage, pp. 32-50.
- ARBER, S. (2001) Designing Samples. In: Gilbert, N. (ed.). *Researching Social Life*. London: Sage, pp. 58-84.
- ARCHBOLD, P.G., STEWART, B.J., MILLER, L.L., HARVATH, T.A., GREENLICK, M., VANNBUREN, L., KIRSCHLING, J.M., VALANIS, B.G., BRODY, K.K. and

SCHOOK, J.E. (1995) The PREP system of nursing interventions: a pilot test with families caring for older members. *Research in Nursing and Health*, 18, pp. 13-16.

ARMITAGE, S. (1990) *Liaison and Continuity of Nursing Care – Executive Summary*. Cardiff: Welsh Office.

ARNSTEIN, S. R. (1969) A Ladder of Citizen Participation. *Journal of the American Institute of Planners*, 35 (4), pp. 216-224.

ARONSON, J. (2002) Elderly people's accounts of home care rationing: missing voices in long-term care policy debates. *Ageing and Society*, 22, pp. 399-418.

ASHWORTH, P.D., LONGMATE, M.A. and MORRISON, P. (1992) Patient participation: its meaning and significance in the context of caring. *Journal of Advanced Nursing*, 17, pp. 1430–1439.

ATWAL, A. (2002) Nurses' perceptions of discharge planning in acute health care: a case study in one British teaching hospital. *Journal of Advanced Nursing*, 39, pp. 450–458.

AUDIT COMMISSION (1995) *United they stand: co-ordinating care for elderly people with hip fracture*. London: HMSO.

BALLINGER, C. and PAYNE, S. (2002) The Construction of the Risk of Falling among and by older people. *Ageing and Society*, 22, pp. 305-324.

BARNES, C., MERCER, M. and SHAKESPEARE, T. (1999) *Exploring Disability: A Sociological Introduction*. Cambridge: Polity Press.

BARNES, M. (2005) The same old process? Older people, participation and deliberation. *Ageing and Society*, 25 (2), pp. 245-259.

BARRON, A. (1990) The right to personal space. *Nursing Times*, 86 (27), pp. 28-32.

BARTH, F. (1967) On the Study of Social Change. *American Anthropologist*, New Series, 69 (6) (Dec., 1967), pp. 661-669. Available at: <http://www.jstor.org/view/00027294/ap020379/02a00020/0> [Accessed on 11/02/2003]

BAUER, I. L. (1994a) *Patients' privacy: exploratory study of patients' perceptions of their privacy in a German acute care hospital*. Aldershot: Avebury Ashgate.

BAUER, I. L. (1994b) Patients' Privacy. *Developments in Nursing and Health Care*, 3.

BAULD, L., CHESTERMAN, J. and JUDGE, K. (2000) Measuring satisfaction with social care amongst older service users: issues from the literature. *Health and Social Care in the Community*, 8 (5), pp. 316-324.

BECK, A.T. and YOUNG, J. E. (1978). College Blues, *Psychology Today*, September, pp. 83-92.

BEISECKER, A.E. (1988) Ageing and the desire for information and input in medical decisions: patient consumerism in medical encounters. *Gerontologist*, 28, pp. 330-335.

BELL, D., BOWES, A. and DAWSON, A. (2007) *Free personal care in Scotland: recent developments*. York: Joseph Rowntree Foundation.

BELL, J. (1999) *Doing Your Research Project: a guide for first-time researchers in education and social science* (3rd edition). Buckingham: Open University Press.

BERESFORD, P., ADSHEAD, L. and CROFT, S. (2007) *Palliative Care, Social Work and Service Users: Making Life Possible*, London: Jessica Kingsley.

BERKMAN, L.F. and KAWACHI, I. (2000) Social Cohesion Social Capital and Health. In Berkman, L.F. and Kawachi, I. (eds) *Social epidemiology*. New York: Oxford University Press, pp.174-190.

BHATTACHARYA, S. (2003) Research funded by drug companies is 'biased'. *New Scientist*, 30 May 2003.

- BIGGS, S. and POWELL, J. (2001), A Foucauldian analysis of old age and the power of social welfare. *Journal of Aging & Social Policy*, 12(2), pp. 93-112.
- BOADEN, N., GOLDSMITH, M., HAMPTON, W. and STRINGER, P. (1982) *Participation in Local Services*. Harlow: Longman.
- BOLCH, D. JOHNSTON, J. B. GILES, L.C. WHITEHEAD, C. PHILLIPS, P. and CROTTY, M. (2005) Hospital to home: an integrated approach to discharge planning in a rural South Australian town. *Australian Journal of Rural Health*, 13(2), pp. 91–96.
- BOLIN, K., LINDGREN, B., LINDSTRÖM, M. and NYSTEDT, P. (2003) Investments in social capital – implications of social interactions for the production of health. *Social Science and Medicine*, 56 (12), pp. 2379-2390.
- BOND, J., COLEMAN, P. and PEACE, S. (1993) *Ageing in Society: An introduction to social gerontology*. London: Sage.
- BORE, J. (1994) Occupational therapy home visits: a satisfactory service? *British Journal of Occupational Therapy*, 57 (3), pp. 85–88.
- BOURDIEU, P. (1973) Cultural reproduction and social reproduction. In: Brown, R. (ed.). *Knowledge, education, and cultural change*. London: Tavistock. pp. 71-112.
- BOURDIEU, P. (1986) Forms of Capital. In: Richardson, J. (ed.). *Handbook of Theory and Research for the Sociology of Education*. New York: Greenwood Press.
- BOURDIEU, P. and PASSERON, J. (1977) *Reproduction in education, society, and culture*. London: Sage Publications.
- BOWLES, K. H., FOUST, J. B. and NAYLOR, M. D. (2003) Hospital discharge referral decision making: a multidisciplinary perspective. *Applied Nursing Research*, 16, pp. 134–143.

BOWLES, K. H., NAYLOR, M. D. and FOUST, J. B. (2003) Patient Characteristics at Hospital Discharge and a Comparison of Home Care Referral. *Decision Journal of the American Geriatric Society*, 50, pp. 336-342.

BOWLING, A. (2002) *Research Methods in Health: Investigating Health and Health Services*. Maidenhead: Open University Press.

BRITISH ASSOCIATION OF SOCIAL WORKERS (2002) *Code of Ethics for Social Work*. Birmingham: BASW.

BRITISH SOCIOLOGICAL ASSOCIATION (2002) *Statement of Ethical Practice* (appendix updated May 04). Available at:
http://www.britisoc.co.uk/user_doc/Statement%20of%20Ethical%20Practice.pdf.
[Accessed on 14/01/06].

BROWN, D., MCWILLIAM, C. and WARD-GRIFFIN, C. (2006) Client-Centred Empowerment Partnering in Nursing. *Journal of Advanced Nursing*, 53 (2), pp.160-168.

BROWN, L. (2003) Evaluating the impact of integrated health and social care teams on older people living in the community. *Health and Social Care in the Community*, 11 (2), pp. 85-94.

BROWN, L., TUCKER, C. and DOMOKOS, T. (2003) Evaluating the impact of integrated health and social care teams on older people living in the community. *Health and Social Care in the Community*, 11(2), pp. 85–94.

BROWN, R. I. (2006) Professional development: education and practice. In: Brown, I. and Percy, M. (eds.). *Intellectual and Developmental Disabilities*. Baltimore: Paul H. Brookes.

BROWNLEA, A. (1987) Participation: myths, realities and prognosis. *Social Science and Medicine*, 25, pp. 605–614.

BULL, M. J. (1992) Managing the transition from hospital to home. *Qualitative Health Research*, 2, pp. 27–41.

BULL, M.J. (1994) Patients' and professionals' perceptions of quality in discharge planning. *Journal of Nursing Care Quality*, 8(2), pp. 47-61.

BULL, M. J. (2000) Discharge planning for older people: a review of current research. *British Journal of Community Nursing*, 5, pp. 70–74.

BULL, M. J., HANSEN, H.E. and GROSS, C.R. (2000) A professional-patient partnership model of discharge planning with elders hospitalized with heart failure. *Applied Nursing Research*, 13, pp.19–28.

BULL, M. J. and KANE, R. L. (1996) Gaps in discharge planning *Journal of Applied Gerontology*, 15, pp. 486-500.

BULL, M.J. and ROBERTS, J. (2001) Components of a proper hospital discharge for elders. *Journal of Advanced Nursing*, 35 (4), pp. 571-581.

BURDEN, B. (1998) Privacy or help? The use of curtain positioning strategies within the maternity ward environment as a means of achieving and maintaining privacy, or as a form of signalling to peers and professionals in an attempt to seek information or support. *Journal of Advanced Nursing*, 27, pp. 15-23.

BURGOON, J. (1982) Privacy and communication. *Communication Yearbook*, 6, pp. 206-249.

BURR, V. (1997) *An Introduction to Social Constructionism*. London: Routledge.

BURSTOW, P., MP, Shadow Secretary of State for Health (2002) *Keep Taking The Medicine 2: The scandal of the over medication of older people in care*. Available at: <http://paulburstow.org.uk/resources/sites/217.160.173.25-3edc7f82c67eb0.46705678/Keep%20Taking%20the%20Medicine%201,%202%20and%203/Keep+Taking+the+Medicine+2.pdf> [Accessed on 11/2/2004].

- BUTLER, I. (2002) A Code of Ethics for Social Work and Social Care Research. *British Journal of Social Work*, 32 (5), pp. 239-248:
- CABINET OFFICE (1999) *Modernising Government*. March 1999, Cm 4310. London: The Stationary Office. Available at: <http://www.archive.official-documents.co.uk/document/cm43/4310/4310-01.htm> [Accessed on: 23/2/2005].
- CAHILL, J. (1996) Patient participation: a concept analysis. *Journal of Advanced Nursing*, 24, pp. 561–571.
- CARPENTER RINALDI, D. (1995) Grounded Theory Research Approach. In Streubert, H. J. and Carpenter Rinaldi, D. (eds) *Qualitative Research and in Nursing: Advancing Humanistic Imperative*. Philadelphia: Lippincott. pp. 145-161.
- CASTELLUCI, D.T. (2004) Perceptions of autonomy in post-stroke elderly clients. *Rehabilitation Nursing*, 29 (1), pp. 24-29.
- CHARMAZ, K. (2000) Grounded Theory: Objectivist and Constructivist Methods. In Denzin, N. and Lincoln, Y. (eds). *Handbook of Qualitative Research*, 2nd Edition. Thousand Oaks, CA. USA: Sage. pp. 509-535.
- CHARMAZ, K. (2006) *Constructing Grounded Theory*. Thousand Oaks, CA. USA: Sage.
- CHEATER, A. (1999) *The Anthropology of Power*. London: Routledge.
- CHENITZ, W. C. and SWANSON, J. M. (1986) *From practice to grounded theory: qualitative research in nursing*. Englewood Cliffs, NJ: Addison-Wesley.
- CHEVANNES, M. (2002) Social construction of the Managerialism of needs assessment by health and social care professionals. *Health and Social Care in the Community*, 10 (3), pp. 168-178.
- CHIOVITTI, R.F. and PIRAN, N. (2003) Rigour and grounded theory research. *Journal of Advanced Nursing*, 44(4), pp. 427–435.

CILLIERS, P. (1998) *Complexity and postmodernism: understanding complex systems*. London: Routledge.

CLARK, M. (1972) Cultural values in later life. In: Cowgill, D.O. and Holmes, L.D. (eds.). *Aging and Modernisation*. New York: Appleton-Century-Crofts. pp. 263-274.

CLARK, P.G. (1996) Communication between provider and patient: values, biography, and empowerment in clinical practice. *Ageing and Society*, 16, pp. 747–774.

CLARK, H., DYER, H. and HARTMAN, L. (1996) *Going Home; Older People Leaving Hospital*. Bristol: Policy Press and Joseph Rowntree Foundation.

CLARK, M., GLASBY, J. and LESTER, H. E. (2004) User involvement in health care research. *Journal of Research Policy and Planning*, 22 (2), pp. 31-38.

CLARK, M., STEINBURG, M. and BISCHOFF, N. (1997) Patient readiness to return home: discord between expectations and reality. *Australian Journal of Occupational Therapy*, 44 (3), pp. 132–141.

CLARKE, A. HANSON, E. J. and ROSS, H. (2003) Seeing the person behind the patient: enhancing the care of older people using a biographical approach. *Journal of Clinical Nursing*, 12(5), pp. 697-706.

CLOSS, J. (1997) Discharge communications between hospital and community health care staff: a selective review. *Health Social Care in the Community*, 5 (3), pp. 181–197.

CLOSS, S.J., STEWART, L.S.P., BRAND, E. and CURRIE, C.T. (1995) A scheme of early supported discharge for elderly trauma patients: the views of patients, carers and community staff. *British Journal of Occupational Therapy*, 58 (9), pp. 373–376.

CLOUGH, R., MANTHORPE, J., OPRSI (GREEN, B., FOX, D., RAYMOND G. and WILSON, P.), RAYMOND, V., SUMNER, K., BRIGHT, L. and HAY, J. (2007) *The support older people want and the services they need*. York: Joseph Rowntree Foundation.

- COFFEY, A. (2006) Discharging older people from hospital to home: what do we know? *International Journal of Older People Nursing*, 1, pp. 141-150.
- COLEMAN, J., BOND, J. and PEACE, S. (1993) Ageing in the Twentieth Century. In Bond, J., Coleman, P. and Pearce, S. (eds) *Ageing in Society: an introduction to social gerontology* (2nd Edition) London: Sage, pp. 1-18.
- COLLOPY, B. (1988) Autonomy in long term care: some crucial distinctions. *Gerontologist*, 28 (suppl.), pp. 10-17.
- COLQUHOUN, D. and KELLEHEAR, A. (eds.) (1993) *Health research in Practice: Political, ethical and methodological issues*. London: Chapman and Hall.
- COMMISSION FOR HEALTHCARE AUDIT AND INSPECTION AND COMMISSION FOR SOCIAL CARE INSPECTION (2003) *Health and Social Care (Community Health and Standards) Act 2003, (Transitional and Consequential Provisions)*. London: The Stationery Office.
- COMMISSION FOR HEALTHCARE AUDIT AND INSPECTION (2006) *Living well in later life: A review of progress against the National Service Framework for Older People*. London: The Stationery Office.
- CONGDON, J. C. (1990) Managing the Incongruities: an analysis of hospital discharge of the elderly. *Communicating Nursing Research 23, Nursing Research- Transcending the 20th Century*. Denver, Colorado: Western Institute of Nursing.
- CONGDON, J.G. (1994) Managing the incongruities: the hospital discharge experience for elderly patients, their families and nurses. *Applied Nursing Research*, 7, pp. 125–131.
- CONTACT THE ELDERLY. Available at: <http://www.contact-the-elderly.org>. [Accessed on 17/05/05].
- CORNER, L. and BOND, J. (2004) Being at risk of dementia: Fears and anxieties of older adults. *Journal of Aging Studies*, 18, pp. 143–155.

CORNES, M. and CLOUGH, R. (2004) Inside Multi-disciplinary Practice: Challenges for Single Assessment. *Journal of Integrated Care Practical evidence for Service development*, 12 (2), April, pp. 3-14.

COULTON, C.J., DUNKLE, R.E., HAUG, M., CHOW, J. and VIELHABER, D.P. (1989) Locus of control and decision making for post hospital care. *Gerontologist*, 29, pp. 627–632.

COWEN, H. (1999) *Community Care, Ideology and Social Policy*. London: Prentice Hall.

COYLE, J. (1999) Exploring the meaning of 'dissatisfaction' with health care: the importance of 'personal identity threat'. *Sociology of Health and Illness*, 21, pp. 95-124.

CRAWFORD, M.J., RUTTER, D., MANLEY, C., WEAVER, T., BHUI, K., FULOP, N. and TYRER, P. (2002) Systematic review of involving patients in the planning and development of health care. *BMJ*, 325(30 November), pp. 1263.

CUMMING, R.G., SALKELD, G., THOMAS, M., and SZONYI, G. (2000) Prospective study of the impact of fear of falling on activities of daily living, SF-36 scores, and nursing home admission. *Journals of Gerontology, Series A Biological Sciences and Medical Sciences*, 55, pp. M299–M305.

CURRAN, P., GILMORE, D.H. and BERINGER, T.R.O. (1992) Communication of Discharge information for elderly patients in hospital. *Ulster Medical Journal*, 61, pp. 56-58.

CUTCLIFFE, J.R. (2005) Adapt or adopt: developing and transgressing the methodological boundaries of grounded theory. *Journal of Advanced Nursing*, 51(4), pp 421–428.

DALLEY, G. (2000) Defining Difference: Health and Social Care for Older People. In: Warnes, A. Warren, L. and Nolan, M. (eds.). *Care Services for Later Life: Transformations and Critiques*. London and Philadelphia: Janet Kingsley. pp. 103-118.

DALY, G. (2001) Citizenship, Public Accountability and Older People: user involvement in community care provision. *Education and Ageing*, 16 (1), pp. 55-75.

DALY, M. (2002) Care as good for social policy. *Journal of Social Policy*, 31, pp. 251–270.

DARLINGTON, Y. and SCOTT, D. (2002) *Qualitative Research in Practice: Stories from the Field*. Birmingham: Open University Press.

Data Protection Act (1998) London: HMSO

DAVIES, N. (2002) Portfolio management and Reflexive practice: Introductory Guidelines (forthcoming).

DAVIES, S., LAKER, S. and ELLIS, L. (1997) Promoting autonomy and independence for older people within nursing practice: a literature review. *Journal of Advanced Nursing*, 26. pp. 408–417.

DAWES, M. SUMMERSKILL, W. GLASZIOU, P. CARTABELLOTTA, A. MARTIN, J., HOPAYIAN, K., PORZSOLT, F., BURKS, A. and ORBORNE, J. (2005) Sicily statement on evidence-based practice, *BMC Medical Education*, 5, pp. 1.

DEAN, H. (1999) Citizenship. In Powell, M. (ed.). *New Labour, New Welfare State?* Bristol: Policy Press.

DE JONG-GIERVELD, J. (1989) Personal relationships, social support and loneliness. *Journal of Social and Personal Relationships*, 6, pp. 197-221.

DENZIN, N. and LINCOLN, Y. (2000) *Handbook of Qualitative Research*. London: Sage.

DEPARTMENT OF HEALTH AND SOCIAL SECURITY (1980) *Inequalities in Health*. The Black Report, Sir Douglas Black. London: The Stationery Office.

DEPARTMENT OF HEALTH (1989a) *Caring for People: Community Care in the Next decade and Beyond*, Cm 849, London: HMSO.

DEPARTMENT OF HEALTH (1989b) *Discharge of Patients from Hospital*, Dh Circ HC (89) 5. London: HMSO.

DEPARTMENT OF HEALTH (1990) *National Health Service (NHS) and Community Care Act*. London: The Stationery Office.

DEPARTMENT OF HEALTH (1992) *The Patient's Charter*. London: HMSO.

DEPARTMENT OF HEALTH (1994) *Hospital Discharge Work Book: A Checklist for Community Based Health and Social Services*. London: HMSO.

DEPARTMENT OF HEALTH (1996) *Community Care (Direct Payments) Act 1996*. London: The Stationery Office.

DEPARTMENT OF HEALTH (1998a) *A first class service: Quality in the new NHS* HSC 1998/113 London: The Stationery Office.

DEPARTMENT OF HEALTH (1998b) *Implementing the recommendations of the Caldicott report* (Consultation paper on "Caldicott guardians" and NHS strategic tracing service) HSC 1998/089. London: Department of Health.

DEPARTMENT OF HEALTH (1998c) *Modernising Social Services*. London: The Stationery Office.

DEPARTMENT OF HEALTH (2000a) *The National Health Service Plan: A plan for investment; a plan for reform*. London: The Stationery Office.

DEPARTMENT OF HEALTH (2000b) *NHS Plan Executive Summary*. London: The Stationery Office.

DEPARTMENT OF HEALTH (2000c) *Promoting independence: partnership, prevention and carers grants - conditions and allocations 2000/2001*. LAC (2000)6. London: The Stationery Office.

DEPARTMENT OF HEALTH (2000d) *No Secrets: Guidance on Developing and Implementing Multi-Agency Policies and Procedures to Protect Vulnerable Adults*, London: HMSO.

DEPARTMENT OF HEALTH (2001a) *National Service Framework for Older People*. London: The Stationery Office. Available at http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4003066&chk=wg3bg0. [Last accessed on 23/05/07].

DEPARTMENT OF HEALTH (2001b) *Research Governance Framework for Health and Social Care*. London: The Stationery Office.

DEPARTMENT OF HEALTH (2001c) *Seeking Consent working with Older People*. London: The Stationery Office.

DEPARTMENT OF HEALTH (2001d) *Your guide to the NHS*. London: The Stationery Office.

DEPARTMENT OF HEALTH (2001e) *The essence of care: patient-focused benchmarking for health care practitioners*. London: The Stationery Office.

DEPARTMENT OF HEALTH (2001f) *The expert patient: a new approach to chronic disease management for the 21st century*. Available at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4006801. [Accessed 14/09/01].

DEPARTMENT OF HEALTH (2001g) *Your Guide To The NHS: Getting the Most from Your National Health Service*. London: The Stationary Office.

DEPARTMENT OF HEALTH (2001h) *The Essence of Care: Patient-focused benchmarking for health care practitioners*. London: The Stationary Office.

DEPARTMENT OF HEALTH (2002a) *Guidance on the Single Assessment Process*. HSC 2002/001: LAC (2002)1. London: The Stationery Office.

DEPARTMENT OF HEALTH (2002b) *The Single Assessment Process: Assessment Tools and Scales*. Available at: www.doh.gov.uk/scg/sap. [Accessed on 27/11/04].

DEPARTMENT OF HEALTH (2002c) *Fair Access to Care Services: Guidance on Eligibility Criteria for Adult Social Care*, LAC(2002)13, London: Department of Health.

Available at:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4009653. [Accessed on: 12/2/04].

DEPARTMENT OF HEALTH (2003a) *Direct Payments Guidance: Community Care Services for Carers and Children's Services (Direct Payment) Guidance England 2003*. London: The Stationery Office.

DEPARTMENT OF HEALTH (2003b) *Community Care (Delayed Discharges, etc.) Act 2003*. London: The Stationery Office.

DEPARTMENT OF HEALTH (2003c) *Discharge from Hospital: Pathway, Process and Practice*. London: The Stationery Office.

DEPARTMENT OF HEALTH (2004a) *The NHS improvement plan: putting people at the heart of public services*. London: The Stationery Office.

DEPARTMENT OF HEALTH (2004b) *Better health in old age: Report from Professor Ian Philp*. Available at:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4092957. [Accessed on: 21/12/04].

DEPARTMENT OF HEALTH (2005a) *Independence, Well-being and Choice: our vision for the future of social care for adults in England*. London: The Stationery Office.

DEPARTMENT OF HEALTH (2005b) *Partnerships for Older People Project*. Available at:

<http://www.dh.gov.uk/en/Policyandguidance/SocialCare/Deliveringadultsocialcare/Olderpeople/PartnershipsforOlderPeopleProjects/index.htm>. [Accessed on 15/12/05].

DEPARTMENT OF HEALTH (2006a) *A new ambition for old age: Next steps in implementing the National Service Framework for Older People*. London: The Stationery Office.

DEPARTMENT OF HEALTH (2006b) *Our health our care our say: a new direction for community services*. London: The Stationery Office.

DEPARTMENT OF HEALTH AND CALDICOTT COMMITTEE (1997) *Report on the review of patient-identifiable information: The Caldicott Report*. 11934. London: HMSO.

DEPARTMENT OF HEALTH AND DEPARTMENT OF ENVIRONMENT, TRANSPORT AND THE REGIONS (1999) *Better care higher standards: a charter for long term care*. London: The Stationery Office.

DEPARTMENT OF HEALTH AND HOME OFFICE (2000) *No Secrets: Guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse*. London: The Stationery Office.

DEPARTMENT OF WORKS AND PENSIONS (2005) *Opportunity Age – Opportunity and security throughout life*. London: The Stationery Office.

DEUTSCHER, I. (1970) Words and Deeds: Social science and social policy. In Filstead, W.J. (ed.) *Qualitative Methodology*. Chicago: Markham.

DEWING J. (2004) Concerns relating to the application of frameworks to promote person-centredness in nursing with older people. *International Journal of Older People Nursing* in association with *Journal of Clinical Nursing*, 13 (3a), pp. 39–44.

- DEY, I. (1993) *Qualitative Data Analysis: A User-Friendly Guide for Social Scientists*. London and New York: Routledge.
- DICKINSON, H., GLASBY, J., FORDER, J. and BEESLEY, L. (2007) Free Personal Care in Scotland: A Narrative Review. *British Journal of Social Work*, 37, pp. 459–474.
- DILL, A.E.P. (1995) The ethics of discharge planning for older adults: an ethnographic analysis. *Social Science and Medicine*, 41, pp. 1289–1299.
- DILL, J. C. and ANDERSON, C.A. (1999) Loneliness, shyness, and depression: The etiology and interrelationships of everyday problems in living. In: Joiner, T. and Coyne, J.C. (eds.). *The interactional nature of depression: Advances in interpersonal approaches*. Washington, D.C.: APA.
- DODD, V. and HUSSAIN, M. (2005) A Forgotten man lay dead in flat for six years. *Guardian*, Wednesday 6th April.
- DOHERTY, C. and DOHERTY, W. (2005) Patients' preferences for involvement in clinical decision-making within secondary care and the factors that influence their preferences. *Journal of Nursing Management*, 13, pp. 119–127.
- DOUCET, A. and MAUTHNER, N.S. (2002) Knowing Responsibly: Linking Ethics, Research Practice and Epistemology. In Mauthner, M., Birch, M., Jessop, J. and Miller, T. (eds) *Ethics in Qualitative Research*. London: Sage.
- DOUGLAS, A. (2000) Going Beyond Lip-service. *Community Care*, 13 July. Available at: <http://www.communitycare.co.uk/Articles/2000/07/13/26836/going-beyond-lip-service.html>. [Accessed on 19/06/05].
- DOWLING, B., POWELL, M. and GLENDINNING, C. (2004) Conceptualising successful partnerships. *Health and Social Care in the Community*, 12 (4), pp. 309–317.

DRISCOLL, A. (2000) Managing post-discharge care at home: an analysis of patients' and their carers' perceptions of information received during their stay in hospital. *Journal of Advanced Nursing*, 31, pp. 1165-1173.

DUNNING, A. (2005) *Information, advice and advocacy for older people: Defining and developing services*. York: Joseph Rowntree Foundation.

EDWARDS, R., RIBBENS, J. with GILLIES, V. (1999) Shifting Boundaries and Power in the Research Process: the example of researching stepfamilies. In: Seymour, J. and Bagguley, P. (eds.). *Relating Intimacies, Power and Resistance*. Macmillan: Basingstoke.

ELLIOT, E. and KIEL, L. D. (1997) Nonlinear Dynamics, Complexity and Public Policy: Use, Misuse, and Applicability. In Eve, R. A., Horsfall, S. and Lee, E. L. *Chaos, Complexity and Sociology: Myths Models and Theories*. London: Sage.

ELLIS, K. (2007) Direct Payments and Social Work Practice: The Significance of 'Street-Level Bureaucracy' in Determining Eligibility. *British Journal of Social Work*, 37, pp. 405–422.

FAULKNER, M. and AVEYARD, B. (2002) Is the sick role a barrier to patient participation? *Nursing Times*, 98 (2).

FAIRHURST K., BLAIR, M., CUTTING J., FEATHERSTONE M., HAYES B., HOWARTH M., ROSE D. and STANLEY I. (1996) The quality of hospital discharge: a survey of discharge arrangements for the over-65s. *International Journal for Quality in Health Care*, 8, pp. 167–174.

FERGUSON, I. (2007) Increasing User Choice or Privatizing Risk? The Antinomies of Personalization. *British Journal of Social Work*, 37, pp. 387–403.

FESTE, C. and ANDERSON, R. (1995) Empowerment: from philosophy to practice. *Patient Education and Counselling*, 26, pp. 139-144.

- FIELDING, N. (1996) Ethnography. In Gilbert, N. (ed.). *Researching Social Life*. London: Sage. pp. 154-172.
- FINCH, J. (1989) *Family obligations and social change*. London: Polity.
- FINCH, J. and MASON, J. (1993) *Negotiating Family Responsibilities*. London: Tavistock/ Routledge.
- FLANAGAN, S.R., RAGNNARSSON, K.T., ROSS, M.K. and WONG, D.K. (1995) Rehabilitation of the geriatric orthopaedic patient. *Clinical Orthopaedics and Related Research*, 316, pp. 80–92.
- FOUCAULT, M. (1965) *Madness and Civilization*. London: Tavistock.
- FOUCAULT, M. (1973) *The Birth of the Clinic: An archaeology of medical perception*. (French original 1963) M. Foucault - 1973 - English reprint. London: Routledge.
- FOUCAULT, M. (1977) *Discipline and Punish*. London: Penguin.
- FOUCAULT, M. (1978) *The History of Sexuality*, Vol.1. London: Penguin.
- FOUCAULT, M. (1980) The Subject of Power. In: Dreyfus, H. and Rabinow, P. (eds.). *Michel Foucault: beyond structuralism and hermeneutics*. Brighton: Harvester.
- FOUCAULT, M. (1991) On Governmentality. In Burchell, G., Gordon, C. and Miller, P. (eds.). *The Foucault Effect*. London: Harvester. pp. 87-104.
- FRANKL, V.E. (1965) *The Doctor and the Soul: from Psychotherapy to Logotherapy*. New York: Bantam.
- FUKUYAMA, F. (1999) *Social Capital and Civil Society*. Available at: <http://www.imf.org/external/pubs/ft/seminar/1999/reforms/fukuyama.htm>. [Accessed: 21/3/07].

GAUTAM, P., MACDUFF, C., BROWN, I. and SQUAIR, J. (1996) Unplanned readmissions of elderly patients. *Health Bulletin*, 56 (6), pp. 449–457.

GENERAL MEDICAL COUNCIL (1998) *Good Medical Practice: Protecting patients, guiding doctors*. London: GMC.

GENERAL MEDICAL COUNCIL (2001) *Good Medical Practice: Duties and responsibilities of doctors*. London: GMC.

GENERAL SOCIAL CARE COUNCIL (2002) *Codes of practice for social care workers*. GSCC September 2002.

GENERAL SOCIAL CARE COUNCIL (2004) *Code of Practice for Social Care Workers and Code of Practice for Employers of Social Care Workers*. GSCC September 2004.

GERGEN, K.J. and GERGEN, M.M. (1991) Towards Reflexive Methodologies. In Steier, F. (ed). *Research and Reflexivity*. London: Sage. pp. 76-96.

GIBSON, B. (2003) Grounded theory. In Miller, R. and Brewer, J. (eds.). *The A to Z of Social Research*. London: Sage.

GIDDENS, A. (1979) *Central problems in Social Theory: Action, Structure and Contradiction in Social Analysis*. London: Macmillan.

GIDDENS, A. (1984) *The Constitution of Society: Outline of the Theory of Structuration*. Cambridge: Polity.

GILBERT, N. (ed.) (1996) *Researching Social Life*. London: Sage.

GISKE, T. and ARTINIAN, B. (2007) A Personal Experience of Working with Classical Grounded Theory: From Beginner to Experienced Grounded Theorist. *International Journal of Qualitative Method*, 6(4).

GLASBY, J. (2003a) *Hospital Discharge: Integrating Health and Social Care*. Oxon: Radcliffe Medical Press Ltd.

GLASBY, J. (2003b) A backward step? *Nursing Older People*, April 15 (2), pp. 6.

GLASBY, J., LITTLECHILD, R., and PRYCE, K. (2004) *Show me the way to go home: delayed hospital discharges and older people: final report*. Birmingham: Health Services Management Centre, University of Birmingham.

GLASBY, J. (2005) Hospital Discharge and Older People: a literature review. *The Research Findings Register*, Summary number 1187. Available at: <http://www.ReFeR.nhs/ViewRecord.asp?ID=1187>. [Accessed on 4/7/07].

GLASER, B. G. (1978) *Theoretical sensitivity: advances in the methodology of grounded theory*. Mill Valley, CA.USA: Sociology Press.

GLASER, B. (1992) *Basics of Grounded Theory Analysis: Emerging versus Forcing*, Mill Valley, CA.USA: Sociology Press.

GLASER, B. (ed.) (1995) *Grounded Theory: 1984–1994*. Mill Valley, CA.USA: Sociology Press.

GLASER, B. (1998) *Doing Grounded Theory: Issues and Discussions*. Mill Valley, CA.USA: Sociology Press. pp. 254.

GLASER, B. G. (2001) *The grounded theory perspective: Conceptualization contrasted with description*. Mill Valley, CA.USA: Sociology Press.

GLASER, B. (2002). Conceptualization: On theory and theorizing using grounded theory. *International Journal of Qualitative Methods*, 1 (2). Article 3 Available at: <http://www.ualberta.ca/~ijqm/>. [Accessed on 17/03/08].

GLASER, B. (2005) *The Grounded Theory Perspective III: Theoretical Coding*. Mill Valley, CA.USA: Sociology Press.

GLASER, B. G. with the assistance of Judith Holton (2004). Remodeling Grounded Theory [80 paragraphs]. Forum Qualitative Sozialforschung / Forum: *Qualitative Social Research*, 5(2), Art. 4. Available at:
<http://www.qualitative-research.net/index.php/fqs/article/viewArticle/607/1315>
[Accessed August 2008]

GLASER, B. and STRAUSS, A. (1967) *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Chicago: Aldine.

GLENDINNING, C., COLEMAN, A. and RUMMERY, K. (2002) Partnerships, performance and primary care: developing integrated services for older people in England. *Ageing and Society*, (22), pp. 185-208.

GLOVER, A. (2005) Implementing the single assessment process. *Journal of Community Nursing*, 19 (10), pp. 11-12.

GOFFMAN, E. (1959) *The Presentation of Self in Everyday Life*. London: Cox and Wyman.

GOLDEN, R.L. AND SONNEBORN, S. (1998) Ethics in Clinical Practice with Older Adults: Recognising Biases and Respecting Boundaries. *Generations*, 22 (3), pp. 82-87.

GRAMSCI, A. (1971) *Selections from the "Prison notebooks"*. Edited and translated [from Italian] by Q. Hoare and G. Nowell-Smith. London : Lawrence and Wishart.

GRANDIS, S., LONG, G., GLASPER, A. and JACKSON, P. (2003) *Foundation Studies for Nursing: Using Enquiry Based Learning*. Basingstoke: Palgrave MacMillan.

GRANT, R. (2005) *What Is Effective Prescribing?* Bath and North East Somerset Primary Care Trust, 9 October 2005. Available at:
<http://www.haiweb.org/medicineprices/2410/contributions/rosGrant.doc>
[Accessed on: 24/11/05].

GROUT, G. (2004) Using negotiated consent in research and practice. *Nursing Older People*, 16 (4), pp. 18-20.

GRUNDY, E. (1997) Progress Report. Demography and Gerontology: Mortality trends among the oldest old. *Ageing and Society*, 19, pp. 713-725.

GUSTAFSSON, B. (2004) *Bekräftande Omvårdnad* (Confirming Nursing). (2nd ed.) Studentlitteratur: Lund. H.

HAIJAR, E. R., HANLON, J.T. and SLOANE, R.J. (2005) Unnecessary Drug Use in Frail Older People at Hospital Discharge. *Journal of the American Geriatrics Society*, 53, pp. 1518–1523.

HAM, C. (2004) *Health Policy in Britain*. 5th Edition. Basingstoke: Pulgrave Macmillian.

HAPP, M. NAYLOR, M. and ROE-PRIOR, P. (1997) Factors contributing to rehospitalization of elderly patients with heart failure. *Journal of Cardiovascular Nursing*, 11, pp. 75-84.

HARDING, J. (1987) Study of discharge communications from hospital doctors to an inner London Practice. *Journal of the Royal College of General Practitioners*, 37, pp. 494-495.

HARDING, J and MODELL, M. (1989) Elderly people's experiences of discharge from hospital. *Journal of the Royal College of General Practitioners*, 39, pp. 17-20.

HARKER, R. (1990) Education and Cultural Capital. In Harker, R., Mahar, C. and Wilkes, C. (eds.). *An Introduction to the Work of Pierre Bourdieu: the practice of theory*. London: Macmillan Press.

HARRIS, J. (2003) *The Social Work Business*. London: Routledge.

HAYDEN, C. and BOAZ, A. (2000) *Making a difference – Better Government for Older People Evaluation Report*. Coventry: University of Warwick Local Government Centre.

HELLSTRÖM, Y. and HALLBERG, I.R. (2001). Perspectives of elderly people receiving home help on health, care and quality of life. *Health and Social Care in the Community*, 9(2), pp. 61-71.

HELP THE AGED (2002) *Nothing Personal: Rationing Social Care for Older People*, Nuffield Community Care Studies Unit, University of Leicester.

HELP THE AGED (2006) *Reaction to review of National Service Framework for Older People*. Available at [http://press.helptheaged.org.uk/_press/Releases/items/healthcare commission press release.htm](http://press.helptheaged.org.uk/_press/Releases/items/healthcare%20commission%20press%20release.htm). [Accessed on 27/3/06].

HELP THE AGED (2009) *Personalisation in Social Care: Progress in the UK and abroad*. London: Help the Aged.

HENWOOD, HARDY, HUDSON AND WISTOW (1997) *Inter-agency collaboration: Hospital Discharge and Continuing Care Sub-study*. Nuffield Institute for Health, Community Care Division

HERTZ, J.E. (1996) Conceptualization of perceived enactment of autonomy in the elderly. *Issues in Mental Health Nursing*, 17. pp. 261-273.

HILL, A. and BRETTLER, A. (2006) Counselling Older People: what can we learn from research evidence? *Journal of Social Work Practice*, 20 (3), pp. 281-297.

HILL, K. KELLARD, K., MIDDLETON, S., COX, L. and POUND, E. (2007) *Understanding resources in later life: Views and experiences of older people*. York: Joseph Rowntree Foundation.

HINSCLIFF, G. (2005) Drugs firms 'creating ills for every pill'. *The Observer* 3/04/05.

HOCKEY, J. and JAMES, A. (1993) *Growing up and growing old: ageing and dependency in the life course*. London: Sage.

- HOCKEY, J. and JAMES, A. (2003) *Social identities across the life course*. Basingstoke: Palgrave Macmillan.
- HOGSTON, R. and SIMPSON, P. (2002) *Foundations of Nursing Practice*. 2nd ed. Houndhills: Palgrave.
- HOLLOWAY, M. (2006) Spiritual need and the core business of social work, *British Journal of Social Work*, 37 (2), pp. 265-280.
- HOLLOWAY, M. and LYMBERY, M. (2007) Editorial- Caring for People: Social Work with Adults in the Next Decade and Beyond. *British Journal of Social Work*, 37 (3). pp. 375–386.
- HORNE, D. (1998) *Getting Better? Inspection of Hospital Discharge (Care Management) Arrangements for Older People*. Wetherby: Social Care Group, Department of Health.
- HORNSBY-SMITH, M. (1993) Gaining Access. In Gilbert, N (ed.). *Researching Social Life*. London: Sage. pp. 52-67.
- HOWLAND, J., PETERSON, E.W., LEVIN, W.C., FRIED, L., PORRDON, D. and BAK, S. (1993) Fear of falling among the community-dwelling elderly. *Journal of Aging Health*, 5(2), pp. 229–243.
- HUBER, D. L. and MCCLELLAND, E. (2003) Patient preferences and discharge planning transitions. *Journal of Professional Nursing*, 19, pp. 204–210.
- HUBY, G., STEWART, J., TIERNEY, A. and ROGERS, W. (2004) Planning older people's discharge from acute hospital care: linking risk management and patient participation in decision-making. *Health, Risk and Society*, 6 (2), pp. 115-131.
- HUGHES, B. (1995) *Older People and Community Care: Critical Theory and Practice*. Buckingham: Open University Press.

HUGHES, M. (2004) Privacy in aged care. *Australasian Journal on Ageing*, 23 (3), Review, pp. 110- 114.

Human Rights Act (1998) London: HMSO

HUNT, S., WISOCKI, P. and YANKO, J. (2003) Worry and use of coping strategies among older and younger adults. *Anxiety Disorders*, 17, pp. 547-560.

HUNTER, M. (2002) Use of homeopathy in NHS not justified. *BMJ*, 9 March 2002, 324, pp. 565.

HUTCHINSON, S. (1986) Grounded Theory in Methodology. In Munhill, P. L. and Oiler, C. (eds), *Nursing Research: A Qualitative Perspective*. Norwalk, CT. USA: Appleton-Century Crofts.

HWANG, H-L., LIN, H-S., TUNG, Y-L. AND WU, H-C. (2006) Correlates of perceived autonomy among elders in a senior citizen home: A cross-sectional survey. *International Journal of Nursing Studies* 43, pp 429–437.

ILLICH, I. (1976) *Limits to medicine: Medical nemesis, the expropriation of health*. Harmondsworth: Penguin Books.

IZARD, C. E. (1972) *Patterns of emotions: A new analysis of anxiety and depression*. New York: Academic Press.

JARY, D. and JARY, J. (2005) *Collins Dictionary of Sociology*. 4th ed. Glasgow: HarperCollins.

JACKSON, M. F. (1990) Use of community support services by elderly people discharged from general medical and geriatric medical wards. *Journal of Advanced Nursing* 15, pp. 167-175.

JEWELL, S.E. (1993) Discovery of the discharge process: a study of patient discharge from a care unit for elderly people. *Journal of Advanced Nursing*, 18, pp. 1288-1296.

JEWELL, S.E. (1996a) Elderly patients' participation in discharge decision making: 1. *British Journal of Nursing*, 5, 914–916, pp 929–932.

JEWELL, S.E. (1996b) Elderly patients participating in discharge decision-making: 2. *British Journal of Nursing*, 5, 1065-1071.

JOHNSON, J. (2002) Taking care of later life: A matter of justice? *British Journal of Social Work*, 32 (6), pp. 739–50.

JORDAN, B. (2004) Emancipatory social work? Opportunity or oxymoron. *British Journal of Social Work*, 34 (1), pp. 5–19.

JOSEPH ROWNTREE FOUNDATION (2004) *Older People Shaping Policy and Practice*. Foundations Summary, October 2004. York: Joseph Rowntree Foundation.

KANE, R. A. (1988) Case management: Ethical pitfalls on the road to high-quality care. *Quality Review Bulletin*, 14, pp. 161-321.

KANE, R. A. (2001) Long-term care and a good quality of life: bringing them closer together. *Gerontologist*, 41, pp. 293–304.

KATBAMNA, S., MARTIN, G. AND PARKER, G. (2002) *Nothing Personal: Rationing Social Care for Older People*, London: Helped the Aged. Available at: http://www2.le.ac.uk/departments/health-sciences/extranet/research-groups/nuffield/project_profiles/001.html/?searchterm=Katbamna%20S [Accessed on February 2005].

KATZ, S. (1996) *Disciplining Old Age: The formation of gerontological knowledge*. Charlottesville: University of Virginia.

KATZ, S. (2000) Busy Bodies: Activity, Aging and the Management of Everyday Life. *Journal of Aging Studies*, 14 (2), pp. 135-152.

KEATING, N., OTFINOWSKI, P., WENGER, C., FAST, J. and DERKSEN, L.

(2003) Understanding the caring capacity of informal networks of frail seniors: a case for care networks. *Ageing and Society*, 23, pp. 115-127.

KEATING, N., SWINDLE, J. and FOSTER, D. (2004) The role of social capital in aging well. *Policy Research Initiative*, Government of Canada. pp. 33.

KENDALL, J. (1999) Axial Coding and the Grounded Theory Controversy
Western Journal of Nursing Research, 21(6), pp. 743-757.

KENNEDY, T. J. T. and LINGARD, L. A. (2006) Making sense of grounded theory in medical education. *Medical Education*, 40 (2), pp. 101–108.

KHARICHA, K., LEVIN, E., ILIFFE, S. and DAVEY, B. (2004) Social work general practice and evidence based policy in the collaborative care of older people: current problems and future possibilities. *Health and Social Care in the Community*, 12 (2), pp. 134-141.

KING, C. and MCMILLAN, M. (1994) Documentation and discharge planning for elderly patients. *Nursing Times*, 90 (20), pp. 31-33.

KOCH, P. (1994) *Solitude: A philosophical encounter*. Chicago: Open Court.

KLOP, R., VAN WIJMEN, F. C. B. and PHILIPSEN, H. (1991) Patient's rights and the admission and discharge process. *Journal of Advanced Nursing*, 16, pp. 408-412.

K ÖHLER, M. (2006) Supporting older people: cold, poor and baffled. *British Journal of Community Nursing*, 11(5), pp. 202-204.

KVAAL, K. and LAAKE, K. (2003) Anxiety and well-being in older people after discharge from hospital. *Journal of Advanced Nursing*, 44 (3), pp. 271–277.

LANE, P. (1990) A measure of clients' perceptions about intrusions of territory and personal space by nurses. In Strickland, O. and Waltz, C. (eds.). *Measuring Client Self-*

care and Coping Skills, Measurement of Nursing Outcomes, Vol. 4. New York: Springer. pp. 199–221.

LATIMER, J. (1993) *Writing Patients, Writing Nursing: The Social Construction of Nursing Assessment of Elderly Patients in an Acute Medical Unit.* PhD Thesis: University of Edinburgh.

LATIMER, J. (1997) Giving patients a future: the constituting of classes in an acute medical unit. *Sociology of Health and Illness*, 19(2), pp. 160-185.

LATIMER J. (1998) Organizing context: nurses' assessments of older people in an acute medical unit. *Nursing Inquiry*, 5, pp. 42-57.

LAWRENCE, R. H., TENNSTEDT, S. L. and KASTEN, L.E. (1998) Intensity and correlates of fear of falling and hurting oneself in the next year: baseline findings from a fear of falling intervention. *Journal of Aging Health*, 10, pp. 267–286.

LEATHARD, A. (ed.) (2003) *Interprofessional Collaboration: From Policy to Practice in Health and Social Care.* London: Brunner-Routledge/Taylor and Francis Group.

LEAVEY, R., WILKIN, D. and METCALFE, D.H.H. (1989) Consumerism and General Practice. *British Medical Journal*, 298, pp. 737–739.

LEE, T. W. (1999) *Using qualitative methods in organizational research.* London: Sage Publications Ltd.

LEGTERS, K. (2002) Fear of falling. *Physical Therapy*, 82 (3), pp. 264 –272.

LEINO-KILPI H., VÄLIMÄKI, M., ARNDT, M. *et al.* (2000) Patients' Autonomy, Privacy and Informed Consent. *Biomedical and Health Research*. 40.

LEINO-KILPI, H., VÄLIMÄKI M., DASSEN, T. GASULL, M., LEMONIDOU, C., SCOTT, A. and ARNDT, M. (2001) Privacy: a review of the literature. *International Journal of Nursing Studies*, 38, pp. 663–671.

- LEWIS, J. (2003) Design Issues. In Ritchie, J. and Lewis, J. (eds.). *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. London: Sage. pp. 47-76.
- LEWIS, J. and GLENNERSTER, H. (1996) *Implementing the New Community Care*. Buckingham: Open University Press.
- LEWIS, J. and RITCHIE, J. (2003) Generalising from Qualitative Research. In: Ritchie, J. and Lewis, J. (eds.). *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. London: Sage. pp. 263-286.
- LI, H. (2005) Hospitalized elders and family caregivers: a typology of family worry. *Journal of Clinical Nursing*, 14, pp. 3–8.
- LINCOLN, Y.S. and GUBA, E.G. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage.
- LLOYD, L. (2006) A Caring Profession? The Ethics of Care and Social Work with Older People. *British Journal of Social Work*, 36(7), pp. 1171–1185.
- LOCHER, J. L., BRONSTEIN, J., ROBINSON, C.O., WILLIAMS, C. and RITCHIE, C.S. (2006) Ethical Issues Involving Research Conducted With Homebound Older Adults *The Gerontologist*, 46, pp. 160-164.
- LOCKE, K. (1996) A funny thing happened! The management of consumer emotions in service encounters *Organization Science*, 7, pp. 40-59.
- LOEBACH WETHERELL, J., MASER, J. D. and VAN BALKOM, A. (2005) Anxiety disorders in the elderly: outdated beliefs and a research agenda. *Acta Psychiatrica Scandinavica*, 111, pp. 401–402.
- LOMBORG, K. and KIRKEVOLD, M. (2003) Truth and validity in grounded theory – a reconsidered realist interpretation of the criteria: fit, work, relevance and modifiability. *Nursing Philosophy*, 4, pp. 189–200

LONG, C. R. and AVERILL, J. R. (2003) Solitude: An Exploration of Benefits of Being Alone. *Journal for the Theory of Social Behaviour*, 33 (1), pp. 0021–8308.

LYMBERY, M. (2004) 'Managerialism and care management practice with older people'. In Lymbery, M. and Butler, S. (eds), *Social Work Ideals and Practice Realities*, Basingstoke: Palgrave.

LYMBERY, M. (2005) *Social Work with Older People: Context, Policy and Practice*. London: Sage.

MACCORMICK, D. (1974) Privacy: A problem of definition. *British Journal of Law and Society*, 1(1), pp. 75–78.

MAGEEAN, R.G. (1986) Study of discharge communications from hospital. *British Medical Journal*, 293, pp. 1283-1284.

MAHONEY, F.I. and BARTHEL, D.W. (1965) Functional Evaluation: The Barthel Index. *Mid State Medical Journal*, 1965 Feb, 14, pp. 61-5.

MAKI, B. E., HOLLIDAY, P. J. and TOPPER, A. K. (1991) Fear of falling and postural performance in the elderly. *Journals of Gerontology, Series A Biological Sciences and Medical Sciences*, 46, pp. M123–M131.

MANTHORPE, J., STANLEY, N., BRADLEY, G. and ALASZEWSKI, A. (1996) Working together effectively? Assessing older people for community care services. *Health Care in Later Life*, 1(3), pp. 143-155.

MARGULIS, S. (2003) On the status and contribution of Westin's and Altman's theories of privacy. *Journal of Social Issues*, 59 (2), pp. 411-429.

MARKS, L. (1994) *Seamless Care or Patchwork Quilt? Discharging Older People from Acute Hospital Care*. London: King's Fund Institute.

- MARSH, C. (1988) *Exploring data: An Introduction to Data Analysis for Social Scientists*. Cambridge: Polity Press.
- MASON, J. (2002) *Qualitative Researching*. 2nd Edition. London: Sage.
- MASON, T. and WHITEHEAD, E. (2003) *Thinking Nursing*. Maidenhead: Open University Press.
- MARTIN, E. (1989) *The Woman in the Body: A Cultural Analysis of Reproduction*. Milton Keynes: Open University Press.
- MARTIN, G.W. (1998) Empowerment of dying patients: the strategies and barriers to patient autonomy. *Journal of Advanced Nursing*, 28 (4), pp. 737-744.
- MARX, K. (1859) *Capital: a critical analysis of capitalist production*. London: S. Sonnenschein, 1902.
- MAXWELL, R. and WEAVER, N. (1984) Introduction. In Maxell R. & Weaver N (eds). *Public Participation in Health: Towards a Clearer View*. London: King's Fund, pp. 9–16.
- MCAULEY, E.M., MIHALKO, S.L. and ROSENGREN, K. (1997) Self-efficacy and balance: correlates of fear of falling in the elderly. *Journal of Aging and Physical Activity*, 5, pp. 329–40.
- MCBRIDE, R.C. (1995) An audit of current discharge planning arrangements and their effectiveness on elderly care wards and community nursing services together with aspects of client satisfaction. *Journal of Nursing Management*, 3, pp. 19-24.
- MCCLYMOT, M.E., THOMAS, S.E. and DENHAM, M.J. (1991) *Health Visiting and elderly people: A health promotion challenge*. (2nd edition). London: Churchill Livingstone.
- MCCORMACK, B. (2001) *Negotiating Partnerships with Older People: A Person-Centred Approach*. Hampshire: Ashgate.

MCCORMACK, B. (2004) Person-centredness in gerontological nursing: an overview of the literature. *Journal of Clinical Nursing*, 13 (suppl.), pp. 31-38.

MCEWEN, J., MARTINI, C.J.M. and WILKINS, N. (1983) *Participation in Health*. Beckenham: Croom-Helm Ltd.

MCINNIS, G. J. and WHITE, J. H. (2001) A Phenomenological Exploration of Loneliness in the Older Adult. *Archives of Psychiatric Nursing*, Vol. XV, No. 3 (June). pp. 128-139.

MCLYMONT, M., THOMAS, S. and DENHAM, M. (1991) *Health Visiting and Elderly People*. Edinburgh: Churchill Livingstone.

MCNABB, D. (2002) *Research methods in public administration and non-profit management: quantitative and qualitative approaches*. Armonk, N.Y.: M.E. Sharpe.

MCWHIRTER, B. (1990) Loneliness: a review of current literature, with implications for counselling and research. *Journal of Counselling and Development*, 68 (4), pp. 417-422.

MCWILLIAM, C. and SANGSTER, J. (1994) Managing patient discharge to home: the challenge of achieving quality of care. *International Journal of Quality in Health Care*, 6, pp. 147-161.

MEANS, R., RICHARDS, S. and SMITH, R. (2003) *Community Care: Policy and Practice*. 3rd Ed. Basingstoke: Palgrave.

MEARA, J. (2004) Ageism and age discrimination. *Age and Ageing*, 33 (6), pp. 646-647

MEARA, J.R., WOOD, J.L., WILSON, M.A. and HART, M.C. (1992) Home from Hospital: a survey of hospital discharge arrangements in Northamptonshire. *Journal of Public Health Medicine*, 14, pp. 145-150.

MEHTA, K.M., SIMONSICK, E.M., PENNINX, B.W., SCHULZ, R., RUBIN, S.M., SATTERFIELD, S., and YAFFE, K. (2003) Prevalence and Correlates of Anxiety

Symptoms in Well-Functioning Older Adults: Findings from the Health Aging and Body Composition Study. *Journal of the American Geriatric Society*, 51, pp. 499–504.

MICHAEL, J. (1994) *Privacy and Human Rights*. Aldershot: Dartmouth Publishing.

MILLS, C. W. (1959) *The Sociological Imagination*. New York: O.U.P.

MINICHELLO, V., BROWNE, J. and KENDIG, H. (2000) Perceptions and consequences of ageism: Views of older people, *Ageing and Society*, 20(3), pp. 253–78.

MISTIAEN, P., DUIJNHOUWER, E., WIJKEL, D., DEBONT, M. and VEEGER, A. (1997) The problems of elderly people at home one week after discharge from the acute setting. *Journal of Advanced Nursing*, 25, pp. 1233-1240.

MOATS, G. (2006) Discharge decision-making with older people: the influence of the institutional environment. *Australian Occupational Therapy Journal*, 53, pp. 107-116.

MORGAN, D., REED, J. and PALMER, A. (1997) Moving from hospital into a care home - the nurse's role in supporting older people. *Journal of Clinical Nursing*, 6(6), pp 463-471.

MORSE, J.M., BARRETT, M. MAYAN, M. OLSEN, K. and SPIERS, J. (2002) Verification Strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods*, 1, Article 2. Available at: http://www.ualberta.ca/~iiqm/backissues/1_2Final/html/morse.html. [Accessed on 21/04/08].

MOUNTAIN G. (1998) *An investigation into the activity of occupational therapists working with the elderly mentally ill*. PhD Thesis. University of Leeds, Leeds.

MOUNTAIN, G. and PIGHILLS, A. (2003) Pre-discharge home visits with older people: time to review practice. *Health and Social Care in the Community*, 11(2), pp. 146-154.

MOYNIHAN, R., HEATH, I. and HENRY, D. (2002) Selling sickness: the pharmaceutical industry and disease mongering. *BMJ*, 324, pp. 886-891.

MOYNIHAN, R. and SMITH, R. (2002) Too much medicine? Almost certainly. *BMJ*, 324, pp. 859-860.

MUNNICHES, J.M.A. (1976) Dependency, interdependency and autonomy: An introduction. In: Munnichs, J.M.A. and Van den Heuval, W.J.A. (eds.). *Dependency and Interdependency in Old Age*. The Hague: Martinus Nijhoff. pp. 3-8.

MURPHY, P. M. and KUPSHIK, G. A. (1992) *Loneliness, Stress and Well-Being*. London: Routledge.

NAYLOR, M., BROOTEN, D., CAMPBELL, R., JACOBSEN, B., MEZEY, M., PAULY, M. AND SCHWARTZ, J. (1999) Comprehensive discharge planning and home follow-up of hospitalized elders. *Journal of the American Medical Association* 281, 613-620.

NCCOP (1978) *Finance and old people's home: Homes Advice Broadsheets no 3*. Sheffield: National Corporation for the Care of Old People

NEILL, J.N., SINCLAIR, I.A.C., GORBACH, P. and WILLIAMS, J. (1985) *Criteria for Part III Care*. Report to the DHSS. London.

NEILL, J. and WILLIAMS, J. (1992) *Leaving Hospital: Elderly People and Their Discharge to Community Care*, National Institute for Social Work, London

NETTLETON, S. AND WATSON, J. (1998) *The Body in Everyday Life*, London: Routledge.

NEVILLE-JAN, A., VERRIER PIERSOL, C. and KIELHOFNER, G. (1993) Adaptive equipment: a study of utilisation after discharge. *Occupational Therapy in Health Care*, 8 (4), pp. 3-14.

NIKOLAUS, T., SPECHT-LEIBLE, N., BACH, M. OSTER, P. and SCHLIERF, G. (1999) A randomized trial of comprehensive geriatric assessment and home intervention in the care of hospitalized patients. *Age and Ageing*, 28, pp. 543-550.

NOLAN, M. (2000) Towards Person-Centred Care for Older People. In Warnes, A. Warren, L. and Nolan, M. (eds.). *Care Services for Later Life: Transformations and critiques*. London and Philadelphia: Jessica Kingsley. pp. 54-74.

NOLAN, M., DAVIES, S. and GRANT, G. (2001) *Working with older people and their families: Key Issues in Policy and Practice*. Buckingham: Open University Press.

NOLAN, M.R., DAVIES, S., BROWN, J., KEADY, J. AND NOLAN, J. (2004) Beyond 'person-centred' care: A new vision for gerontological nursing. *International Journal of Older People Nursing*, 13 (3a). pp. 45-53.

NURSING AND MIDWIFERY COUNCIL (2002) *Code of Professional Conduct*. London: NMC.

OAKLEY, A. (1993) *Essays on Women, Medicine and Health*. Edinburgh: Edinburgh University.

O'CAITHAN, A. (1994) Evaluation of a hospital at home scheme for the early discharge of patients with fractured neck of femur. *Public Health Medicine*, 16 (2), pp. 205-210.

O'DONNELL, M. and ENTWISTLE, V. (2004) Consumer involvement in decisions about what health-related research is funded. *Health Policy*, 70, pp. 281-290.

OFFICE FOR NATIONAL STATISTICS (2002) *Social Trends*, 32. London: The Stationary Office.

OFFICE FOR NATIONAL STATISTICS (2003) *Census 2001: Key statistics for local authorities in England and Wales*. London: OfNS.

OFFICE FOR NATIONAL STATISTICS (2006) *Life expectancy at birth by health and local authorities in the United Kingdom, 1991-1993 to 2003-2005*. National Statistics Website Release, 21st November 2006 [Accessed on 03/06/07] Available at: http://www.statistics.gov.uk/downloads/theme_population/LE_Report_Nov06.pdf

OFFICE FOR NATIONAL STATISTICS (2007) *Life Expectancy at Birth, 2003-2005*. London: OfNS.

OLDMAN, C. (2002) Later life and the social model of disability: a comfortable partnership? *Ageing and Society*, 22. pp. 791-806.

OLIVER, M. AND BARNES, C. (1998) *Disabled People and Social Policy*. Harlow: Longman Press.

PALMORE, E. B. (2003) Ageism Comes of Age. *Gerontologist*, 43 (3), pp. 418-419.

PANORAMA (2003) *A Carer's Story*, BBC 1, Monday 3 November.

PANORAMA (2009) *Britain's Homecare Scandal*, BBC 1, Thursday 9 April.

PARKINSON, W. (2004) Multi-disciplinary person-centred care: Has government policy helped or hindered. *Nursing Older People*, 16 (7).

PARKER, G. and SEYMOUR, J. (1998) Male carers in marriage: Re-examining feminist analysis of informal care. In Popay, J., Hearn, J. and Edwards, J. (eds.). *Men, masculinities and gender in welfare*. London: Routledge. pp. 181-195.

PARROTT, R., BURGOON, J.K., BURGOON, M. and LEPOIRE, B.A. (1989) Privacy between physicians and patients: more than a matter of confidentiality. *Social Science and Medicine*, 29. pp. 1381-85.

PARSONS, T. (1951) *The Social System*. New York: Free Press.

- PARTON, N. (2003) Rethinking professional practice: The contributions of social constructionism and the feminist ethics of care, *British Journal of Social Work*, 33(1), pp. 1–16.
- PEARSON, P., PROCTER, S., WILCOCKSON, J. and ALLGAR, V. (2004) The process of hospital discharge for medical patients: a model. *Journal of Advanced Nursing*, 46(5), pp. 496–505.
- PHILP, I. (2002). Developing a National Service Framework for Older People. *Journal of Epidemiology and Community Health*, 56, pp. 841-842.
- PHILP, I. (2007) *A Recipe for Care – Not a Single Ingredient: Clinical case for change*. Gateway 7768. London: Department of Health.
- PIERCE, L. L., WILKINSON, L. K. and ANDERSON, J. (2003) Analysis of the Concept of Aloneness as Applied to Older Women Being Treated for Depression. *Journal of Gerontological Nursing*, 29 (7), pp. 20-25.
- PIERSON, J. (2001) *Tackling Social Exclusion*. New York: Routledge.
- PLATT, D. (2004) How we'll knock down service barriers. *Guardian*, 10th May 2004.
- "P.M." Radio 4 10th November 2004
- POLIT, D. F. and HUNGLER, B. P. (1999) *Nursing research: principles and methods*. Philadelphia, PA.: Lippincott.
- POWELL, J. L. (2001) Theorizing Gerontology: The Case of Old Age, Professional Power and Social Policy in the United Kingdom. *Journal of Aging & Identity*, 6 (3), pp. 117-135.
- POWELL, J. and BIGGS, S. (2000) Managing Old Age: The Disciplinary Web of Power, Surveillance and Normalization. *Journal of Aging and Identity*, 5 (1), pp. 3-13.

POWELL, J. and BIGGS, S. (2003) Foucauldian Gerontology: A Methodology for Understanding Aging. *Electronic Journal of Sociology* [On-line]. Available at: http://epe.lac-ac.gc.ca/100/201/300/ejofsociology/2003/v07n02/03_powell_biggs.html [Accessed on: 31/3/06].

POWELL, J., ROBISON, J., ROBERTS, H. AND THOMAS, G. (2007) The Single Assessment Process in Primary Care: Older People's Accounts of the Process. *British Journal of Social Work* 37(6), pp 1043-1058.

POWERS, P. (2003) Empowerment as Treatment and the Role of Health Professionals. *Advances in Nursing Science*, 26 (3). pp. 227- 237.

PREEN, D. B., BAILEY, B.E.S., ALAN WRIGHT, A., KENDALL, P., PHILLIPS, M., HUNG, J., HENDRIKS, R., MATHER, A. AND WILLIAMS, E. (2005) Effects of a multidisciplinary, post-discharge continuance of care intervention on quality of life, discharge satisfaction, and hospital length of stay: a randomized controlled trial. *International Journal for Quality in Health Care*, 17. pp. 43–51.

PROCTOR, M. (1996) Measuring Attitudes. In: Gilbert, N. (ed.). *Researching Social Life*. London: Sage. pp. 116-134.

PUTNAM, R. (1995) Bowling Alone: America's declining social capital. *Journal of Democracy*, 6(1). pp. 65-78. Available at: <http://xroads.virginia.edu/~hyper/DETOC/assoc/bowling.html> [Accessed on: 26/02/07].

QUETZAL TRITTER, J. and MCCALLUM, A. (2006) The snakes and ladders of user involvement: Moving beyond Arnstein, *Health Policy* 76(2), pp156-168.

QUINN, A., SNOWLING, A., and DENICOLO, P. (2003) *Older people's perspectives* York: Joseph Rowntree Foundation.

RANDERS, I. and MATTIASSON, A-C. (2004) Autonomy and integrity: upholding adult patients' dignity. *Journal of Advanced Nursing*, 45, pp. 63–71.

RAYNES, N., CLARK, H. and BEECHAM, J. (eds.). (2005) *The report of the Older People's Inquiry into 'That Bit of Help'*. York: Joseph Rowntree Foundation.

REED, J., COOK, G., CHILDS, S. and HALL, A. (2003) *Getting old is not for cowards: Comfortable, healthy ageing*. York: Joseph Rowntree Foundation.

REED, J., COOK, G., BOLTER, V. and DOUGLAS, B. (2006) *Older people 'getting things done': Involvement in policy and planning initiatives*. York: Joseph Rowntree Foundation.

RICHARDS, S. (2000) 'Bridging the Divide': Elders and the assessment process. *British Journal of Social Work*, 30 (1), pp. 37-49.

RICHARDS, S. and COAST, J. (2003) Interventions to improve access to health and social care after discharge from hospital: a systematic review. *Journal of Health Services Research and Policy*, 8 (3), pp. 171-179.

RITCHIE, J., SPENCER, L. and O'CONNOR, W. (2003) Carrying out Qualitative Analysis. In: Ritchie, J. and Lewis, J. (eds.). *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. London: Sage. pp. 219-262.

RITCHIE, J., LEWIS, J. and ELAM, G. (2003) Designing and Selecting Samples. In: Ritchie, J. and Lewis, J. (eds.). *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. London: Sage. pp. 77-108.

ROBERTS, E., ROBINSON, J. and SEYMOUR, L. (2002) *Old Habits Die Hard: Tackling Age Discrimination in Health and Social Care*. London: King's Fund.

ROBERTS K. (2000) Interaction with Providers of Health and Social Care: a function of the demographic and socio-economic characteristics of elderly people. *Education and Ageing*, 15, pp. 177-193.

ROBERTS, K. (2002) Exploring participation: older people on discharge from hospital. *Journal of Advanced Nursing*, 40 (4), pp. 413-420.

ROBERTS, P. (2004) Sharing and Collaboration. *Nursing Researcher*, 11 (2) pp. 3.

ROBERTS, K. (2006). Participation in interest-based learning is filled with “positive for young children, *Bottomlines*, 4(2). Available at:

http://www.wbpress.com/index.php?main_page=index&cPath=1 [Accessed on 18/04/08].

ROCHON, P. A. and GURWITZ, J. H. (1997) Optimising drug treatment for elderly people: the Prescribing Cascade. *BMJ*, 25 October; 315, pp. 1096-1099.

ROE, B., WHATTAM, M., YOUNG, H. and DIMOND, M. (2001) Elders' perceptions of formal and informal care: aspects of getting and receiving help for their activities of daily living. *Journal of Clinical Nursing*, 10(3), pp. 398–405.

ROOSA, W. (1982) Territory and privacy: Residents' views: findings of a survey. *Geriatric Nursing*, 3, pp. 241–43.

ROPER, N., LOGAN, W.W. and TEIRNEY, A.J. (1980) *The Elements of Nursing*, London: Churchill Livingstone.

ROSS, F., DONOVAN, S., BREARLEY, S., VICTOR, C., COTTEE, M., CROWTHER, P. AND CLARK, E. (2004) Involving older people in research. *Health and Social Care in the Community*, 13 (3), pp. 268-275.

RUSSELL, D. (1996) ULCA Loneliness Scale (version 3): reliability, validity, and factor structure, *Journal of Personality Assessment*, 66 (1), pp. 20–40.

RYAN, M. C. and PATTERSON, J. (1987) Loneliness in the elderly. *Journal of Gerontological Nursing*, 13, pp. 6-12.

RYDEMAN, I. and TORNKVIST, L. (2006) The patient's vulnerability, dependence and exposed situation in the discharge process: experiences of district nurses, geriatric nurses and social workers. *Journal of Clinical Nursing*, 15, pp. 1299–1307.

- SANG, B. (2003) Patient and public participation in health systems: some basic principles. In Doohar, J. and Byrt, R. (eds.). *Empowerment and the Health Service User*, Vol 2. Wiltshire: Mark Allen. pp. 51-59.
- SAVAGE, E.B. (1998) *An examination of the changes in the professional role of nursing outside Ireland: a report prepared for the commission on Nursing*, Dublin: The Stationery Office.
- SCHÖN, D. (1991) *The Reflective Practitioner: How professionals think in action*. Arena: London.
- SCHOPP, A., LEINO-KILPI, H., VÄLIMÄKI, M., DASSEN, T., GASULL, M., LEMONIDOU, C., SCOTT, P. A., ARNDT, M. and KALJONEN, A. (2003) Perceptions of privacy in the care of elderly people in five European countries. *Nursing Ethics*, 10 (1), pp. 39-47.
- SCHUSTER, E.A. (1976) Privacy, the patient and hospitalisation. *Social Science and Medicine*, 10, pp. 245–248.
- SCOTT, P.A., VÄLIMÄKI, M., LEINO-KILPI, H., DASSEN, T., GASULL, M., LEMONIDOU, C. AND ARNDT, M. (2003a) Autonomy, privacy and informed consent 1: concepts and definitions. *British Journal of Nursing*, 12 (1), pp. 43-47.
- SCOTT, P.A., VÄLIMÄKI, M., LEINO-KILPI, H., DASSEN, T., GASULL, M., LEMONIDOU, C. and ARNDT, M. (2003b) Autonomy privacy and informed consent 3: elderly care perspective. *British Journal of Nursing*, 12 (3), pp. 158-168.
- SCOURFIELD, P. (2002) Reflections of gender, knowledge and values in social work, *British Journal of Social Work*, 32(1), pp. 1–15.
- SCOURFIELD, P. (2005) Implementing the Community Care (Direct Payments) Act: Will the Supply of Personal Assistants meet the Demand and at what Price? *Journal of Social Policy* 34(3), pp 469-488.
- SEVENHUIJSEN, S. (1998) *Citizenship and the Ethics of Care*, London, Routledge.

SHAKESPEARE, P. (1993) *Reflecting On Research Practice: Issues in Health and Social Welfare*. Buckingham: Open University Press.

SHANG, A., HUWILER-MÜNTENER, K., NARTEY, L., JÜNI, P., DÖRIG, S., STERNE, J.A., PEWSNER, D. and EGGER, M. (2005) Are the clinical effects of homoeopathy placebo effects? Comparative study of placebo-controlled trials of homeopathy and allopathy. *Lancet*, Aug 27-Sep 2; 366 (9487), pp. 726-32.

SHANNON , C. (2004) As the patient voice grows louder, it is time to see who's listening *Health Service Journal*, 114, pp.12-13.

SHAW, A. and SHAW, I. (2001) Risk in a Risk Society. *Research Policy and Planning*, 19 (1), pp. 3-16.

SHILLING, C. (1993) *The Body and Social Theory*, London: Sage

SHEPPERD, S., PARKES, J. MCCLARAN, JJM. and PHILLIPS, C. (2004) Discharge Planning from hospital to home *Cochrane database of systematic reviews*, 1. Art No.: CD000313.

SHIELL A., KENNY, P. and FARNWORTH, M.G. (1993) The role of the clinical nurse coordinator in the provision of cost effective orthopaedic services for older people. *Journal of Advanced Nursing*, 18, pp. 1424–1428.

SILVERMAN, D. (2001) *Interpreting qualitative data: methods for analyzing talk, text and interaction*. 2nd ed. London: Sage

SIM, J. and WRIGHT, C. (2000) *Research in Health Care: Concepts, Design and Methods*. Cheltenham: Stanley Thornes Ltd.

SIMMS, M. (2004) A theory of age exclusion through closure: 'Chronological age' to 'clinical need'. *Journal of Aging Studies*, 18, pp. 445-465.

SIMMONS, R. (2001) Questionnaires. In Gilbert, N. (ed.). *Researching Social Life*. London: Sage. pp. 85-104.

SIMPSON, R. (2003) Participation of Older People and their Carer's in Care. In Doohter, J. and Bryt, R. (eds.). *Empowerment and the Health Service User, Vol 2*. Wiltshire: Mark Allen. pp. 134-145.

SINCLAIR, I. (1988) The Client Reviews: Elderly. In Sinclair, I. (ed) *Residential Care: The Research Reviewed*. London: HMSO.

SKEET, M. (1970) *Home from Hospital: a study of home care needs of recently discharged hospital patients*. London: Dan Mason Nursing Research Committee.

SKEET, M. (1974) *Home from hospital: the result of a survey conducted among recently discharged hospital patients*. The Florence Nightingale Memorial Committee.

SMITH M., ROUSSEAU B.A., LECOUTURIER J., GREGSON B., BOND J. and RODGERS H. (1997) Are older people satisfied with discharge information? *Nursing Times*, 93, pp. 52-53.

SOCIAL EXCLUSION UNIT (2006) *Sure Start in Later Life: Ending inequalities for older people*. Office of the Deputy Prime Minister. The Stationary Office: London.

SOCIAL RESEARCH ASSOCIATION (2003) *Ethical Guidelines*. Available at: <http://www.the-sra.org.uk/documents/pdfs/ethics03.pdf>. [Accessed on: 21/4/04].

SOLOVE, D.J. (2002) Conceptualizing privacy. *California Law Review*, 90, pp. 1087–1155.

STACEY, C. L. (2005) Finding dignity in dirty work: the constraints and rewards of low wage home care labour. *Sociology of Health & Illness*, 27 (6), pp. 831-854.

STEADMAN, P.H. (1991) On the Relations between Seeing, Interpreting and Knowing. In: Steier, F. (ed.). *Research and Reflexivity*. London: Sage. pp. 53-62.

STORR, A. (1989) *Solitude: A return to the self*. New York: Ballantine.

STRAUSS, A. (1987) *Qualitative Analysis for social scientists*. New York: Cambridge University Press.

STRAUSS, A. and CORBIN, J. (1990) *Basics of qualitative research grounded theory procedures and techniques*. Newbury Park: Sage.

STRAUSS, A. and CORBIN, J. (1994) Grounded Theory: an overview. In Denzin, N. and Lincoln, Y. (eds), *Handbook of Qualitative Research*. London: Sage. pp 273-285.

STRAUSS, A. and CORBIN, J. (1998) *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. 2nd Edition. London: Sage.

SUTHERLAND, S. (1999), With respect to old age: long term care – rights and responsibilities., *The Final Report of the Royal Commission on Long Term Care for the Elderly*, Chairman. Professor Sir Stewart Sutherland, Cm 4192-I, London: The Stationary Office.

SWAIN, J., GILLMAN, M. and FRENCH, S. (1998) *Confronting Disabling Barriers: Towards Making Organisations Accessible*. Birmingham: Venture Press

SWAIN, J., FRENCH, S. and CAMERON, C. (2003) *Controversial Issues in a Disabling Society*. Open University Press: Maidenhead.

TANNER, D. (2003) 'Older people and access to care', *British Journal of Social Work*, **33**(4), pp. 499–515.

TANNER, D. (2007) Starting with Lives: Supporting Older People's Strategies and Ways of Coping. *Journal of Social Work*, **7** (1), pp. 7-30.

TAPPEN R.M., HALL R.F., STAHURA P. and BLUME L.(1995) Adequacy of preparation for discharge from the rehabilitation units of a long-term care institution. *Rehabilitation Nursing Research*, **4**, pp. 98-103.

TAYLOR, B. and DONNELLY, M. (2006) Risks to home care workers: professional perspectives. *Health, Risk and Society*, 8(3), pp 239-256.

TELLEGEN, A. (1985) Structures of mood and personality and their relevance to assessing anxiety with an emphasis on self-report. In: Tuma, A.H. and Maser, J. D. (eds.). *Anxiety and the anxiety disorders*. Hillsdale, New York: Erlbaum. pp. 681-706.

TENNSTEDT, S, HOWLAND, J, LACHMON, M, PETESON, E, KASTEN, L and JETTE, A. (1998) A randomized, controlled trial of a group intervention to reduce fear of falling and associated activity restriction in older adults. *Journals of Gerontology, Series B: Psychological Science and Social Sciences*, 53, pp. 384–392.

THANE, P. (1996) *Foundations of the Welfare State*. London: Longman.

THATCHER, M. (1987) Interview with *Women's Own Magazine*, October 31st 1987.

TIERNEY, A. J. (ed.) (1993) *Discharge of Patients from Hospital: Report of a Survey of Current Practice in Acute Hospital Wards in Scotland and Concurrent national Surveys of the Experiences and Views of Community Nursing Staff and General Practitioners*. Nursing Research Unit, Department of Nursing Studies, University of Edinburgh, Edinburgh.

TIERNEY, A. and CLOSS, J. (1993) Discharge planning for elderly patients. *Nursing Standard*, 7, pp. 30–33.

TIERNEY, A., CLOSS, S., HUNTER, H. and MACMILLAN, M. (1993) Experiences of elderly patients concerning discharge from hospital. *Journal of Clinical Nursing*, 2, pp. 179-185.

TINETTI, M. E. and POWELL, L. (1993) Fear of falling and low self-efficacy: a case of dependence in elderly persons. *Journal of Gerontology*, 48. pp. 35–38.

- TOMASSINI, C. (2005) *Population trends 2005*. Population and Demography Division, Office for National Statistic, GAD.
- TOWNSEND, P. (1981) The Structured Dependency of the Elderly: creation of social policy in the twentieth century. *Ageing and Society*, pp. 1 -8.
- TOWNSEND, J., DYER, S., COOPER, J., MEADE, I., PIPER, M. and FRANK, A. (1992) Emergency hospital admissions and readmission of patients aged over 75 years and the effects of a community based discharge scheme. *Health Trends*, 24 (4), pp. 136–139.
- TOWNSEND, J. PIPER, M. FRANK, A. O., DYER, S., NORTH, W. R. and MEADE, T. W. (1988) Reduction in hospital readmission stay of elderly patients by a community based hospital discharge scheme: a randomized controlled trial. *British Medical Journal*, 297, pp. 544-547.
- TRACY, M. and RONAYNE, T. (2000) *Achieving Inclusion: The role of empowerment in policy and practice*. Dublin, Ireland: WRC Social and Economic Consultants.
Available at: <http://www.iol.ie/EMPLOYMENT/integra/publications.html>. [Accessed on 17/12/06].
- TRAVERS, A. F. (1996) Caring for Older People: Carers. *BMJ*, 24 August 1996 (313), pp. 482-486.
- TRONTO, J. (1993) *Moral Boundaries: A Political Argument for an Ethic of Care*. London: Routledge.
- TULLOCH, A.J., FOWLER, G.H., MCMULLAN, J.J. and SPENCE, J. (1975) Hospital discharge reports: contents and design. *British Medical Journal*, 4, pp. 443-446.
- TURNER, B.S. (1992) *Regulating Bodies: Essays in Medical Sociology*. London, New York: Routledge.
- TWIGG, J. (2002) The body in social policy: mapping a territory. *Journal of Social Policy*, 31, pp. 421–439.

TWIGG, J. and ATKIN, K. (1994) *Carers Perceived: Policy and Practice in Informal Care*. Milton Keynes: Open University Press.

UNGAR, M. (2001) The Unapologetic Qualitative Social Work Researcher: a critical look at research questions and methods. *Social Work and Social Sciences Review*, 9 (2), pp. 17-24.

VAN BAARSEN, B., SNIJDERS, T. A.B., SMIT, J.H. and VAN DUIJN, M.A.J. (2001) Lonely but not alone: emotional isolation and social isolation as two distinct dimensions of loneliness in older people. *Educational and Psychological Measurement*, 61 (1), pp. 119-135.

VICTOR, C.R., HEALY, J., THOMAS, A. and SEARGANT, J. (2000) Older patients and delayed discharge from hospital. *Health Social Care in the Community*, 8 (6), pp. 443-452.

VICTOR, C. *et al.* (2000) Being alone in later life: loneliness, social isolation and living alone. *Reviews in Clinical Gerontology*, 10. pp. 407-417.

VICTOR C.R. and VETTER N.J. (1988) Preparing the elderly for discharge from hospital: a neglected aspect of patient care? *Age and Ageing* 17, pp. 155-163.

VICTOR, C. R., YOUNG, HUDSON, M. and WALLACE, P. (1993) Whose responsibility is it anyway? Hospital admission and discharge of older people in an Inner London District Health Authority. *Journal of Advanced Nursing*, 18, pp. 1297-1304.

WALKER, A. (1982) Dependency and Old Age. *Social Policy and Administration*, 16, pp. 115-135.

WALKER, C., HOGSTEL, M. O. and COX CURRY, L. (2007) Hospital Discharge of Older Adults: How nurses can ease the transition. *American Journal of Nursing*, 107 (6), pp. 60-70.

WALSH, K. and KOWANKO, I. (2002) Nurses' and patients' perceptions of dignity. *International Journal of Nursing Practice*, 2002 (8), pp. 143-151.

WANLESS, D. (2006) *Securing Good Care for Older People: Taking a long-term view*. London: Kings Fund.

WARNES, A. M. (1993) Being Old, Old People and the Burdens of Burden. *Ageing and Society*, 13 (3), pp. 297.

WATERS, K. (1987) Discharge planning: an exploratory study of the process of discharge planning on geriatric wards. *Journal of Advanced Nursing*, 12, pp. 71-83.

WATERS, K., ALLSOPP, D., DAVIDSON, I. and DENNIS, A. (2001) Sources of support for older people after discharge from hospital: 10 years on. *Journal of Advanced Nursing*, 33 (5), pp. 575-582.

WATERWORTH, S. and LUKER, K. (1990) Reluctant collaborators: do patients want to be involved in decisions concerning care? *Journal of Advanced Nursing*, 15, pp. 971-976.

WATSON, D., CLARKE, L.A. and CAREY, G. (1988) Positive and negative affectivity and their relation to anxiety and depressive disorders. *Journal of Abnormal Psychology*, 97, pp. 346-353.

WEISS, R.S. (1973) *Loneliness: the experience of emotional and social isolation*. Cambridge, Mass: MIT Press.

WENGER, G.C. (1994) *Support Networks of older people: a guide for practitioners*. Bangor: CSPRD (Joseph Rowntree Foundation).

WENGER, G.C. (1996) Social networks and gerontology. *Reviews in Clinical Gerontology*, 6, pp. 285-293.

WENGER, G.C. (1997) Social networks and the prediction of elderly people at risk. *Ageing and Mental Health*, 1 (4), pp. 311-20.

- WENGER, G.C. and TUCKER, I. (2002) Using Network Variation in Practice: Identification of support Network Type. *Health and Social Care in the Community*, 10 (1), pp. 28-35.
- WEST, M. (1999) Communication and teamwork in health care. *Nursing Times Research*, 4, pp. 8-16.
- WEST, C. and FRANKEL, R.M. (1991) Miscommunication in medicine. In Coupland, N., Giles, H. and Wiemann, J.M. (ed.s) *'Miscommunication' and Problematic Talk*. Newbury Park: Sage, pp. 166–194.
- WESTIN, A.F. (1967) *Privacy and Freedom*. New York: Atheneum.
- WIFFIN, A. (1995) An assessment of procedures. *Nursing Times*, 91 (28), pp. 31-32.
- WILKIN, D. (1990) Dependency. In Peace, S.M. (ed.). *Researching Social Gerontology*. British Society of Gerontology. London: Sage. pp. 19-31.
- WILLIAMS, G. (2007) Should medical journals carry drug advertising? No. *BMJ*, 14 July 2007 (335), pp. 75.
- WILLIAMS, E.I., GREENWELL, J. and GROOM, L.M. (1992) The care of people over 75 years old after discharged from hospital: An evaluation of timetabled visiting by Health Visitor Assistants. *Journal of Public Health Medicine*, 14, pp. 138-144.
- WILLIAMS, E.I. and FITTON, F.(1988) Factors affecting early unplanned readmissions of elderly patients to hospital *British Medical Journal*, 297, 784-787.
- WILLIAMS, E.I. and FITTON, F. (1990) General Practitioner response to elderly patients discharged from hospital. *BMJ*, 300, pp. 159-161.
- WILLIAMS, E.I. and FITTON, F. (1991) Use of nursing and social services by elderly patients discharged from hospital. *British Journal of General Practice*, 41, pp. 72-75.

WOOGARA, J. (2001) Human rights and patients' privacy in UK hospitals. *Nursing Ethics*, 8, pp. 234-245.

WOOGARA, J.R. (2005) Patients' privacy of the person and human rights. *Nursing Ethics*, 12 (3), pp. 273-287.

WORTH, A., TIERNEY, A.J., MACMILLAN, M.S., KING, C. and ATKINSON, F.I. (1993) *A National Survey of Community Nursing Staff's Experience and Views Relating to Discharge of elderly people following acute hospital care*. Report on Discharge of Patients from Hospital, Nursing Research Unit, Department of Nursing Studies, University of Edinburgh, Edinburgh, Scotland.

WUEST, J. (2006) Grounded theory: the method. In Munhall, P. L. (ed.) *Nursing research: a qualitative perspective* (4th Edition), London: Jones & Bartlett Publishers, pp. 239- 272.

YOUNGER COMMITTEE (1972) *Report of the Committee on Privacy*. Cmnd 5012, Sir Kenneth Younger (Chairman). London: HMSO.

YOUNG, E. (2001) Medical journals tackling 'excessive control' of drug companies. *New Scientist*, 10 September 2001.

APPENDICES

- APPENDIX 1** Interview topic guides.
- APPENDIX 2** Consenting to interview.
- APPENDIX 3** Information leaflet.
- APPENDIX 4** Consenting to providing access to assessment.
- APPENDIX 5** Dependency Classification Matrix (Wilkin 1990).
- APPENDIX 6** Wenger's model of hospital discharge and network type (1997).

APPENDIX 1: Interview topic guides

Interview A Topic Guide

What preparations are you making for your return home?

Who is helping you get things organised?

What are the main things you need support with?

Are their people at home (family/friends/neighbours) to help you?

Are you looking forward to going home?

Interview B Topic Guide

Do you feel you were asked about things with which you needed support?

How have you been managing since you came home?

Is it how you expected it to be?

Have you come across problems since you came home with which you would like some help?

Have you been getting the help you need to live at home?

Is there anything about the care in the hospital that you thought was particularly good or difficult?

Did you choose to come back to your own home after hospital?

Are there any changes to your routine, comparing before you were admitted to hospital and now you are back at home?

Were you included in decisions about the help you get?

Interview C Topic Guide

How have you been managing since you came home from hospital?

What support are you getting from health and social services staff?

Do you get the support you feel you need?

Have you had any problems since you came home that you have not been able to discuss?

Are there problems that you have found living at home with which you would like support?

Do you feel older people are given enough support/ the right support when leaving hospital for home?

APPENDIX 2: Consenting to interview
CONSENT FORM 1

Going Home: Leaving Hospital Care

This form is to help us check that I have mentioned everything to you that you might want to know about this study.

It is also to show that you have agreed to be interviewed and that I have explained to you what is involved in taking part.

One copy will be kept for our records and one copy is for you to keep.

Have the following points been explained clearly to you?

- You are free to withdraw from this study at any time without giving a reason.
- You have received an information sheet about this study.
- You understand the research will involve 3 interviews, one before you leave hospital and two after you go home.
- The interview will be audio taped.
- Anything you tell me will be kept confidential unless we discuss otherwise.

I understand the above points and give my consent to be interviewed for this project.

Name:..... Date:.....

Signature:

Name:.....

Signature:.....

Contact details: **Clare Whitfield, Dept of Nursing, Social Work and Associated Health Studies, University of Hull HU6 7RX. Tel: 01482 346311 ex: 6334.**

Some Background Information

The government has introduced a new way of finding out what help you feel you need when you are going home from hospital.

Before an older person goes home they take part in an assessment. This is a way you and those who help you, including any family or friends, will be able to work out what support you feel you need at home. The change here is that each person has a greater say in what problems they are helped with.

The idea is to treat each person as an individual, looking at all needs and trying to provide a package of care that suits an individual's personal situation best.

It is hoped that these changes will allow you a bigger say in what happens when you leave hospital.

Going Home from Hospital?

You are invited to take part in a research study.

Before you decide it is important that I explain why this research is being done and what it will involve. Please take some time to read the information leaflet and talk about it to others if you wish.

Please feel free to ask me if there is anything that is not clear or you would like more information. Take time to decide whether or not you would like to take part.

Who am I?

My name is Clare Whitfield.

You can contact me through:

**Department of Nursing, Social Work and
Associated Health Studies, University of Hull HU6
7RX Or phone me on (01482) XXXXXX**

What this study is about.

This study is to find out about your experiences of planning your return home and of going home and looks at three main areas:

- How much of a 'say' you felt you had when organising your return home.
- How the arrangements for going home worked out.
- How you feel about the arrangements for care that you have been offered or receive.

What taking part will mean

Taking part in the study would involve talking to me about your experiences of getting ready for your return home from hospital and how well you thought the planning worked.

- I would like to meet for three of these discussions
- During the panning of your after hospital care.
 - Within the first week of you going home.
 - When you have been back in your home for about two months

With your permission, I will tape our conversations on audio tape but all the information you give me will be confidential.

What's in it for you?

This research study is a way of looking at how well planning your return home works. The best way is to ask you! Although I will not be involved in helping with your discharge planning, it does give you the opportunity to have your say and it might even be fun!

APPENDIX 4: Consenting to providing access to assessment

CONSENT FORM 2
Going Home: Leaving Hospital Care

This form is for you to give me permission to use assessments made by the nurses, doctors and other members of the team in your preparation for home. One copy will be kept with my research details and one copy is for you to keep

To understand the way older people are assessed by nurses and other health care staff, I would like to be able to draw upon assessments made by staff helping you prepare yourself for the return home.

- I would like to reassure you of the following:
- You are free to withdraw from this study at any time without giving a reason
- Strict confidentiality will be observed at all times
- Your name and identifying details will not be used without separate and explicit consent
- Anything you tell me will be kept confidential unless we discuss otherwise.

I understand the above points and give my consent for assessment details to be accessed.

Name:..... Date:.....

Signature:

Name:..... Signature:.....

Contact details: **Clare Whitfield, Dept of Nursing, Social Work and Associated Health Studies, University of Hull HU6 7RX Tel: 01482 346311 ex: 6334.**

APPENDIX 5: Dependency Classification Matrix

CAUSES OF DEPENDENCY	CATEGORIES OF NEED										
	Orientation	Activities of daily living	Mobility	Occupation	Social integration	Economic	Emotional	Environmental	Other		
Life-cycle dependency											
Dependency of crisis (excluding disablement)											
Dependency resulting from disablement											
Dependency as a personality trait (Neurotic dependency)											
Socially/culturally defined dependency											

Source: WILKIN, D. (1990) Dependency. In Peace, S.M. (ed.) *Researching Social Gerontology*. British Society of Gerontology. London: Sage, pp. 19-31.

APPENDIX 6: Wenger's model of hospital discharge and network type (1997)

Support network	Typical circumstances	Significance for practice
Locally integrated	Local relative will usually provide care Friends and neighbours support and visit Shared care makes it possible to return home Welcome from family, friends and neighbours Emotional support	<ul style="list-style-type: none"> ○ Supporters may need reassurance/skill sharing ○ Community nursing for specialised care
Wider community focused	Short-term acute admission most common Family may visit from distance for short-term help and support Visiting family may deflect community nursing after-care Friends provide emotional support and visit Long-term care problematic unless spouse Preparations may be made by relatives, neighbours or friends Friends may withdraw at higher levels of dependency	<ul style="list-style-type: none"> ○ Community nursing may not be activated if family available on discharge, but this is likely to be quite short-term ○ Interventions to provide practical help will reinforce friendship network
Local self-contained	If no spouse, likely to return to an empty house If no spouse, informal care likely to be short-term if it materialises Relative support likely to be minimal/short-term Neighbours likely to monitor	<ul style="list-style-type: none"> ○ Spouse carer may need support ○ Home may need airing, heating, cleaning before discharge ○ Community nursing help, including personal care ○ Monitoring ○ Increased domiciliary support may be needed
Local family dependent	Spouse or relative in the same household; or relative in nearby household Other family visit/support Likely to return home at higher levels of impairment/disability, maybe for terminal care Family will be welcoming and preparations made	<ul style="list-style-type: none"> ○ Carer support may need to be reviewed/increased ○ Community nursing inputs may need to be long-term
Private restricted	In absence of spouse, no informal care likely Spouse carer maybe isolated May return to an empty home	<ul style="list-style-type: none"> ○ Preparation of home may be neglected ○ Carer may need support ○ Community nursing support needed at least in the short-term ○ Domiciliary support at least in short-term, if living alone

Suitability of housing/accommodation should be assessed in all cases