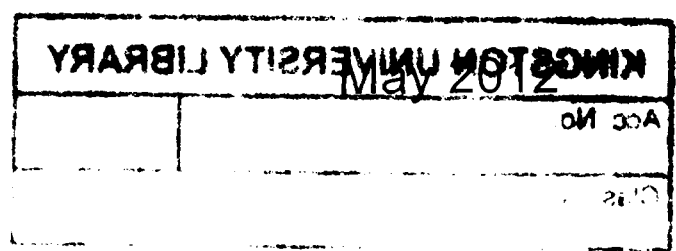


Perspectives of Decision Making in a UK Care Home: A Grounded Theory Study

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Abstract

Older people resident in care homes are amongst the most vulnerable and dependent in any society. This study aimed to explore perspectives on decision making in a care home in the United Kingdom (UK), considering the appropriateness of who made the decisions, how and under what authority. It used grounded theory methodology in a case study framework, in a single care home. Field work was conducted between December 2009 and January 2011 in an inner metropolitan area. Participants were twenty one residents, eight relatives, five registered nurses and six care workers. Data were collected using; interviews; informal conversations; observation and examination of documentation. Participants' perspectives were considered through a values based lens with emphasis on autonomy and dignity as the most dominant in policy, ethical discourse, professional and empirical literature. Findings were constructed from systematic analysis of the data. Two central phenomena were identified, resident as decision maker and others decide for resident. Decisions were categorised into three types, everyday, infrequent and advance decisions. Each group of participants viewed different decision types as most important. Staff appeared to have little knowledge of policy and law and notably, they appeared not to consider mental capacity in relation to decision making, nor did they demonstrate recognition of the ethical dilemmas they faced. All participants found it difficult to articulate values underpinning decision making. Despite staff accepting that residents were able to make decisions and had a right to do so, residents' preferences were not always respected. There was a tension between staff's desire to offer choice, the need to minimise risk and provide good care within the constraints of the organisation with a finite number of staff. If operationalised, the value of solidarity could help relieve the tension and potential dissonance experienced by actors in the care home under study and similar care home environments. Solidarity promotes mutuality and reciprocity which would allow all actors to be recognised and valued, ultimately benefiting the residents' quality of life.

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Chapter 1

Introduction

Older people with physical and mental disabilities who live in care homes, are dependent on others for their basic needs. In this sense they are some of the most potentially vulnerable in our society. Exploration of the ways in which decisions are made by and for them is important. The thesis explores decision making in care homes for older people, investigating whether residents have the choice and control they desire, who makes decisions on behalf of residents, when and how and under what authority they make them.

This opening chapter introduces the thesis. It begins by explaining the context and rationale for the study. It provides information on group residences known as care homes in the United Kingdom (UK), starting with a definition. It includes information on care homes, who runs, lives and works in them. Care home regulations and policy drivers are discussed. The need for care homes as a place to provide care for today's older people is considered. A definition of decisions and choice follows. The study aims and research questions are then presented. The next section considers my own position as the researcher within the project. Finally, an outline of the thesis is given.

1.1 Context of Group Residences for Older People

1.1.1 Definition of a UK care home

A care home in England and Wales was defined in the Care Standards Act (2000) as: an establishment providing accommodation together with nursing or personal care for persons who are ill, disabled or infirm, have a mental disorder, or are dependent on drugs or alcohol and is not a hospital, independent clinic or children's home. In Scotland the Regulation of Care (Scotland) Act (2001) provided a similar definition. Care homes are registered to provide different levels of care, either for personal care only which consists of assistance with washing, dressing and provision of medication, or personal care with nursing, which requires that a registered nurse is on duty twenty four hours a day. In Northern Ireland care homes are known as either residential or nursing homes. the former providing social care, the latter 24 hour nursing care.

1.1.2 The care home population and demand for places

The UK population is ageing, with the fastest population growth being amongst those over 80. Cracknal (2010), in Key Issues for the New Parliament, reported the projection for this age group to almost double by 2030 and is set to reach 8 million by 2050. The Office of Fair Trading (OFT) (2005) stated that in 2004 there was an estimated 410,000 people living in approximately 15,700 care homes. This is greater than the 138,074 overnight beds available in the National Health Service (NHS) (Department of Health (DoH) 2012) which have been steadily falling over the last 20 years (Kings Fund 2010). Laing and Buisson (2010a), who provide authoritative independent commentaries on market trends in the healthcare industry, reported on private and voluntary homes and indicated that in this sector in April 2010 the number of residents in care homes was increasing. There was an estimated 474,400 older and physically disabled people living in approximately 13,130 care homes. Most older people do not live in any type of residential care but by the time they reach the age of 90 about one quarter of people reside in such homes (Laing and Buisson 2010a). Thus, Laing and Buisson (2010a) predicted that there will be 3.5 million people over the age of 85 by 2036 and more people will be living in care homes.

There is concern that an ageing population will put a strain on the UK economy in the payment of pensions, additional health care and long term care needs (Office for Budget Responsibility 2011). Cohen (2011) commented on the Office for National Statistics (2010) report suggesting that the ageing population will lead to a significant tax burden on future generations. However, the impact of an ageing population is not a new concern. Katz (1996) recounted reports of an economic and moral crisis due to the growing aged population at the end of the nineteenth and beginning of the twentieth centuries. Nevertheless, Mullan (2002) argued that ageing is not a social problem. He noted that over many years there have been reports that it would be impossible to support the ageing population but, as society continues to provide pensions and health and social care, these claims have been shown to be false.

The ageing population is not the only demographic change which will have an impact on the demand for care home places for older people. Laing and Buisson (2010a) identified other important issues: the willingness of family members to provide informal care, health and dependency in very elderly people and the changing expectations of older people using the services. Relating to the first point, the NHS Information Centre Social Care

Team (2010) reported that there are 5 million carers in England alone, the majority of these being women. Laing and Buisson (2010a) suggested that women may continue to abandon traditional roles, such as caring for elderly relatives, due to such issues as divorce and remarriage, smaller families, greater mobility, and more women working outside the home. However, this is not a new situation and Laing and Buisson (2010a) found little empirical evidence to show that these changes have led to people changing their caring behaviour. Nonetheless, in his report into future health care trends recommended by the Treasury and commissioned by the Kings Fund, Wanless (2006) considered that, based on current trends, it is unlikely that informal care will increase enough to fill future demand.

The health problems and dependency levels of older people will affect the need for care home placements. The Parliamentary Office of Science and Technology (POST) (2006) considered the concept of healthy life expectancy rather than simply life expectancy. The former considers the number of years a person lives free from debilitating conditions with reasonable independence. POST (2006) suggested that the difference between healthy life expectancy and overall life expectancy gives an indication of the need for long term care. They drew attention to the uncertainty about the future, whether there will be a compression in morbidity, in that the period of ill health or disability will be shorter resulting in an older but healthier population. Laing and Buisson (2010a) noted that there is no consensus on whether the optimistic hypothesis of compression of morbidity is correct, but suggested improvement in treatments for chronic conditions, particularly dementia, would have a significant effect. It can thus be concluded that, the need for long term care may not increase despite increased longevity.

The preference of older people for care in their own homes may also be a factor in demand for care home places. Wanless (2005) suggested that the baby boomers (those born between 1945 and 1954) will be more demanding than current service users. POST (2006) identified a worst case scenario where ill health and disability remains the same or increases, resulting in a longer period of morbidity prior to death, putting increasing pressure on health and social care services, carers and the community in their attempt to care for this growing number of older people who are disabled or in ill health. However they, among other commentators, suggested it is premature to predict that such a scenario is inevitable.

1.1.3 Care home residents

The majority of care home residents are female (partly because women live longer than men), aged over 80 with clinical condition(s) rather than just frailty, and have no partner at home (Laing and Buisson 2010a). Bowman, Whistler and Ellerby (2004) in their 2003 survey of BUPA homes found that 44% of residents were immobile, only 22% had a mental state that was described as “normal” and 50% were doubly incontinent.

Approximately 40% of people in care homes in the independent sector were self funding. About 8% were funded by the NHS, while the remainder received their funding from Local Authorities (LA) (Laing and Buisson 2010a). Self funders generally had to pay more than publicly funded residents due to the strong purchasing power of LAs (Laing and Buisson 2010a). However, about 28% of LA funded residents paid a “third party top up” whereby a person can be placed in a more expensive home and a family member can pay the difference.

1.1.4 The care home population and dementia

Luengo-Fernandez, Leal and Gray (2010) estimated that over 820,000 people in the UK have dementia and about 37% of those live in care homes. POST (2006) reported that between 62 and 74% of residents in care homes have dementia. Iliffe et al (2009) believed that dementia remains under diagnosed in primary care. OFT (2005) reported that 43% of care home admissions were due to mental health problems but this does not consider the number of people who develop cognitive problems after admission. The large number of people with cognitive impairment in care homes provides a challenge to those working there. Staff have to respond to symptoms such as changes in mood and behaviour that can be unpredictable, residents with dementia can become angry and aggressive or depressed and apathetic (Nuffield Council on Bioethics 2009).

Dementia care is the largest specialist area in care homes for older people but only about 57% of people admitted with dementia as the reason, are cared for in specialist units (Laing and Buisson 2010a). This does not include the many people who are admitted with other conditions and also have dementia, or those who develop dementia after entering care (Laing and Buisson 2010a). Dementia care delivered in a specialist unit with staff trained to care for this group of residents is therefore the exception rather than the rule.

1.1.5 Statistics on care homes

The average number of beds in a care home is 36, a number that has grown steadily over the last two decades. Care homes with nursing make up 4,803 of the homes, with the majority (4,264) being in the for profit sector. The average number of places in homes with nursing is 49, while in homes providing only social care the average is 28 (Laing and Buisson 2010a). Since the end of the Second World War there has been an aim to move to smaller institutions and Netten et al (2005) cited evidence that the most positive social environments were found in smaller homes. The need for economy of scale has led to smaller homes closing and new homes increasing in size (Laing and Buisson 2010a).

1.1.6 Care home staff

The number of staff working in care homes is not known. However, the workforce is known to be largely female and often part time (Laing and Buisson 2010b). These factors have contributed to the problem of recruitment and retention of staff. In England the overall number of vacancies was a little over 3% (although this was higher in care staff than in higher grades) and the turnover, 18%, was also higher in care workers (Eborall, Fenton and Woodrow 2010). Consequently, a large number of migrant workers now work in the care sector. Hussein, Manthorpe and Stevens (2011) reported that 68% of care workers in London are non-British born.

Working in care homes, whether as a nurse or as a care worker, is often seen as a low status occupation. Machin and Wilson (2004) stated that the job of care assistant is one of the lowest paid occupations in the economy. The majority of care homes' costs go on staff, mostly direct nursing and care staff, (Laing and Buisson 2010b). Wanless (2006) described the social care work force as minimally qualified and poorly trained. He also discussed the mainly negative perception of social care staff held by all sectors of the public, with this view being reinforced by the media.

Nolan et al (2004) noted that working with older people is often perceived as low status and less exciting and important than other areas of nursing. COI Communications (2001) found that the staff considered themselves undervalued by society and that media reports had led to negative stereotyping. However, staff considered their work valuable and they were committed and dedicated.

1.1.7 Regulation in UK care homes

There is a requirement that all care homes in the UK are registered with the appropriate body. For England and Wales this is the Care Quality Commission (CQC). The manager must also be registered and should be fit to carry out the duties of a care home manager. Care homes must be registered with National Care Standards Commission in England, the National Assembly for Wales, the Scottish Commission for the Regulation of Care in Scotland or the Regulation and Quality Improvement Authority in Northern Ireland.

Care homes for older people are subject to National Minimum Standards (2004) in Wales, National Care Standards: Care Homes for Older People (2007) in Scotland, in Northern Ireland (NI) there are two separate sets of standards both published in 2008, Nursing Home Standards and Residential Care Homes Standards. In England the Health and Social Care Act 2008 introduced the Essential Standards of Quality and Safety which apply across both the health and social care sectors and care homes must “show that they are meeting essential standards of quality and safety” (CQC 2010a). In all UK jurisdictions, regulations cover similar issues and compliance with these standards is a legal requirement. Among the values that the English legislation affirms; service users should be respected and involved in their care and treatment, ensuring that they have information and are encouraged and, where necessary, assisted to express what is important to them and their views accommodated where practicable (The Health and Social Care Act 2008 (Regulated Activities) Regulations 2010). These values are evident in all standards across the UK. The centrality of the right for residents to make their own decisions and lead their lives according to their individual wishes is clearly indicated. The CQC performs inspections to ensure that all care homes comply with the standards. This function is carried out by the Care Commission in Scotland and the Regulation and Quality Improvement Authority in Northern Ireland.

Staffing levels in England are governed by the “essential standards of quality and safety”, which require the numbers and skill-mix of staff to match the assessed needs of residents. Although a formula has been devised (Residential Forum 2002), Dudman (2007) identified some shortcomings in that it does not specify the percentage of qualified nurses needed in care homes, nor are these regulations easily enforceable. The National Minimum Standards required staff to receive training and gain a qualification (usually NVQ) but this is difficult to meet where there is a large turnover of staff. However, by

2009 over 85% of homes had achieved the minimum standard of 50% of care staff having an NVQ level 2 or higher (Eborall, Fenton and Woodrow 2010). The English system is now based on outcomes rather than process so inspections assess whether staff are providing care in an appropriate manner rather than concentrating on what training they have received. As the number of inspections has decreased with the new legislation (Laing and Buisson 2010a) this will be even more difficult to judge.

1.1.8 The current need for care homes

The provision of home care has increased and most people stated that they would prefer to live in their own home (Croucher 2008). This challenges whether residential care is the best way of providing care for older people. The Wagner Report (1988) concluded that entry to a care home should be a choice with information on the alternatives. This promotion of choice sounds ideal but as Laing and Buisson (2010a) reported most admissions to care homes were arranged by someone other than the prospective resident, casting doubt on whether it was an active choice for those entering care.

Wanless (2006), in his report commissioned by the Kings Fund to look into future funding for social care, explained that the government of the day aimed to promote choice, independence and prevention (providing care to people with lower needs to avoid hospitalisation and the need for long term care) for older people (DoH 2005, DoH 2006c). However, despite the preference by most older people to receive home care (Croucher 2008), the public spending on home services has risen more slowly than the public spending on residential care. About 20% of the LA budget for social care was spent on home care while about 45% went on residential care (Commission for Social Care Inspection 2005). Hudson and Henwood (2009) suggested that private funding of care consisted of around 35% of spending. The Fair Access to Care Services has, since 2002, attempted to reduce unfairness in the provision of social care in the home (DoH 2002 and DoH 2010d). As these guidelines have been operationalised, LAs have had to universalise the level of need at which they will fund support in the home (low, moderate, substantial or critical needs). Many LAs have raised the threshold for eligibility for public funding to substantial (e.g. Lambeth Adults' and Community Services 2006) which could increase admissions to residential care.

Professor Harwood (2004), a Consultant Geriatrician who has researched and published widely on a variety of topics relating to older people's health and care, suggested that with

the will and the resources, theoretically anyone could be cared for at home. However, although most people would prefer to remain at home this does not apply to everyone. Resources are not finite and Harwood (2004) noted that home care can be more expensive than a care home. Further, he noted that there are circumstances such as a person living alone with dementia with poor awareness, who may be unsafe and have fluctuating care needs where it would be extremely difficult to care for them at home. Bowman, Whistler and Ellerby (2004) suggested that mental frailty and incontinence, both of which are experienced by the majority of care home residents, make care in the community impractical or at least prohibitively expensive.

Consequently, there will always be some need for care home places for those who choose it and for those who cannot receive the necessary care in their own home. As far back as 1962, Townsend, in his influential work, considered residential care a poor way of caring for older people. Nevertheless, he accepted that the most infirm would still need care in a residential setting.

Catastrophic predictions about the cost of an ageing population bear some responsibility for a lack of investment in the improvement of long term care. After five literature reviews on discrimination in health and social care services conducted in 2007 and 2009, the Centre for Policy on Ageing (CPA) (2010) suggested that institutional ageism is responsible for providers of social care believing that older people will accept an inferior quality of life than that expected by the rest of the population. Dudman (2007) suggested that there has been ageism in policy relating to long term care, concentrating on managing decline rather than looking for positive ways to ensure that older people can maximise their quality of life. The CPA (2010) suggested this is due to lack of resources and a historical legacy of ageism, which meant inferior services had become the norm. They also opined that the strict eligibility criteria for public funding of social care had led to service providers ignoring emotional, psychological, social and spiritual needs to provide only for physical needs, resulting in a diminution of the quality of life for many older people to whom these multifarious needs are most important. As a result, events over the last 80 years demonstrate that it has been public scandals in institutional care for older people that have been the impetus for calls for change.

1.1.9 Public scandals as a driver for change

Throughout the twentieth century, concerns have been raised at regular intervals about the quality of care delivered in residential care settings for older people. It has often been scandals that have driven change in policy and generated recommendations for improvement to practice. Despite statutory regulations and standards laid down by regulators there have been doubts about the standard of care delivered to care home residents. These concerns have been identified through investigations by consumer organisations, journalists and charities, although this is not an exhaustive list.

The Nursing Home Registration Act 1927 followed the Select Committee Report of 1926 that disclosed scandals and irregularities which once revealed could not be ignored (Braithwaite, Makkai and Braithwaite 2007). The 1960s saw the publication of the well known work by Townsend (1962), *The Last Refuge* and Robb's *Sans Everything* (1967), they both described grim institutions with poor quality of life for residents. Since the 1960s successive governments have had to deal with publicly revealed scandals in the quality of care but the pace of change has been slow (Open University 2011). More recently the Kings Fund conducted a comprehensive inquiry into care services for older people in London and found an underfunded, poorly staffed system which provided little in the way of choice and often poor quality care (Robinson and Bank 2005). In 2006 the Dignity in Care Campaign was launched by the DoH (2006a) as reports of undignified care continued to surface. The Which? (2011) Care Homes Investigation found poor care in care homes for older people including inadequate food and unsafe environments. A journalist, Andy Bloxham, in a national daily newspaper (Daily Telegraph 2011), reported substandard care in care homes giving statistics on deaths from falls, infections and malnutrition. Campaigners stated that if standards of care and supervision were sufficiently high, people would not be dying of preventable causes such as falls and pressure sores (Bloxham 2011).

The Alzheimer's Society (2010) responded to the Nursing and Midwifery Council (NMC) (2010) review of preregistration education, expressing concern about the care of people with dementia. They identified an unacceptable variation in care with unskilled staff "who are desperate for training" (Alzheimer's Society 2010 p2).

The perennial nature of public scandals suggests that there has been considerable complacency, amongst both providers of care and regulators, despite the laws regulating care homes, the many policy changes and the recommendations for improvement to practice.

As well as the physical care of residents there have been concerns about residents' emotional, social and psychological well-being. The My Home Life¹ literature review (Dudman 2007) identified that quality of life differs from the quality of care but is equally, if not more important to residents. They reported that maximising residents opportunities to make choices is important to quality of life.

The project by Bowers et al (2009) entitled, "Older people's vision of long-term care", explored the voice, choice and control of older people with high support needs. Commissioned by the Joseph Rowntree Foundation Independent Living Committee, it explored the challenge in identifying issues important to residents' experience of a good life, with research and literature concentrating on services and care. They suggested that these important issues have been overlooked as, "the language of 'voice, choice and control' is still new and almost alien to this sector i.e. long-term care" (Bowers et al 2009 p17).

The concern for people to be involved in choices about their own care has become central in the discourse on long term care.

1.2 Definitions of decision and choice

So far I have used the words decision and choice with the presumption that they are well understood concepts. In the empirical literature on care homes in the UK there is little discussion of what is meant by 'decision' or 'choice'. Often decision and choice are used interchangeably, as is often the case in everyday speech. Considering the dictionary definition, choice is the act of choosing or selecting and to choose is "to select...from a number of alternatives" (Collins English Dictionary 1997 p287). To decide is "to reach a decision" (Collins English Dictionary 1997 p410), a decision is "1. a judgement, conclusion, or resolution reached or given: verdict, 2. the act of making up one's mind"

¹ My home life is an "initiative aimed at improving the quality of life of those who are living, dying, visiting and working in care homes." My Home Life (2012)

(Collins English Dictionary 1997 p411). Thus, choice is merely about selecting from a given list whereas a decision requires deeper deliberation.

In a concept analysis Noone (2002 p27) defined decision making as “the selection of a salient alternative or acceptable solution.” The defining attributes being.

1. An intentional choice between two or more discrete options
2. Based on recognition of a stimulus for action
3. Commits a person to a path of action
4. Expects to accomplish a specific goal or goals (Noone 2002 p27).

Hastie and Dawes (2009) suggest that a decision is a response to a situation with three parts;

1. It has more than one possible course of action;
2. The decider can consider future events or outcomes following the decision based on degrees of beliefs or probabilities;
3. The possible outcomes and consequences can be evaluated against personal goals and values.

Hastie and Dawes (2009) also provided a list of what can be construed as decisions as an adjunct to this explanation. These decisions have potentially significant consequences for the person deciding and sometimes for others. Thus, although a minor decision about everyday life, for example what to wear, may fit the three parts contingent to a decision, the list of decisions appears to exclude this simple ‘choice’.

A different perspective on the division between the meaning of the words choice and decision appears in the work by Rachin (1989) and the review of his book by Stolarz-Fantino and Fantino (1990). Here, decisions relate to the cognitive process while choice is the behavioural component.

Choice and decision making can be analysed from different perspectives in various disciplines; psychology, cognitive sciences, economics, business and law to name a few. It can and does sometimes mean different things in various specialities and usages, a discussion of this is out of the scope of this thesis. Decision making in this thesis is intended to mean any choice or decision as I consider both worthy of examination in relation to their effect on the lives of older people in care homes. The words have been

used interchangeably as they so often are in everyday speech, but the use of the word decision or choice is largely guided by the word used in the literature, whether policy documents, empirical or theoretical literature. The meaning for participants about decisions and choice will be clarified in the findings chapters, but some said they did not make any decisions but agreed, for example, that they had both chosen and/or decided what time to get up that morning. The words spoken and understood by participants have been used in this context.

1.3 The study aims and research questions

I have followed a career in nursing, mostly working with older people in care homes. I was aware of the growing discourse on the care of older people and their right to make choices. I therefore aimed to explore the process and influences on everyday and significant decision making on older people living in care homes. I aimed to do this in the context of current policy and discourse, and to assess the implications for practice. As the study developed the following research questions were posed;

1. What decisions are made in care homes?
2. Who makes the decisions and with what authority and/or responsibility?
3. What are the barriers and facilitators for residents to making their own decisions and what factors influence relatives' involvement?
4. To what extent is the policy and public discourse of values in decision making reflected in the practice of staff?

The next section considers the importance of my own position in this study. Recognition of my central position and reflexivity has been important to ensure openness and veracity.

1.4 The researcher within this study

Within this study I have used qualitative methodology under the interpretive paradigm. As Finlay (2002) observed, the researcher is central in qualitative research in that she affects the collection, selection and interpretation of data. Finlay (2002) noted that the researcher will inevitably influence the responses of participants and shape the findings. As the

researcher and the participants negotiate the meaning. another researcher would locate a different story. Blaikie (2009) believed that reflexivity is not optional but obligatory for all social researchers no matter their ontological and epistemological beliefs or the methodology they use. I agree with the view expressed by Gilgun (2005) that writing with an anonymous third person voice can be in opposition to the very essence of the research. Horsburgh (2003) suggested that the use of the first person whenever they are personally involved when writing up a research project can demonstrate reflexivity on the part of the researcher. I view reflexivity as central to this enquiry and discuss it further in chapter 3. 3.4.6.

Thus, I have been aware of my need for reflection, and more importantly, reflexivity from the start of this study. I felt it was important that I was open about my part in this project and consequently I have written myself into the thesis using the first person narrative wherever I considered myself to be a significant actor, i.e. wherever I made personal judgements, decisions or observations and where my thoughts and actions directly affected the research process. A more formal academic style has been adopted elsewhere.

With my concern to ensure reflexivity it is important that early in this thesis I explain who I am and why I conducted this study. I am a registered nurse, educated in the UK and I have worked as a staff nurse in care homes, which has given me a particular interest in the optimal and ethical care of older people in such homes. More personally, my mother suffered with dementia and spent the last three years of her life in care homes. Although she was generally well cared for, I was aware that care could be improved. I hoped that I would be able to improve practice in care homes through my research.

I undertook a Masters in Social Research Methods and in Ethics and Law. Consequently, I have knowledge of a number of disciplines and their theoretical backgrounds. However, rather than grounding my research in one of these disciplines, as a nurse. I have tried to use a pragmatic approach and combined theories from the areas I have studied as the background to this project. I believe this was the most appropriate way of using my knowledge and education to its best advantage.

1.5 The outline of the thesis

Chapter 2 reviews the empirical literature on decision making conducted in UK care homes. It explores the evidence on, what decisions are made, who makes them and with what authority and responsibility. It further investigates the facilitators and barriers for residents making their own decisions, as well as the factors affecting relatives' involvement. It finally considers the central position of autonomy and dignity in the discourse on the care of older people. It finishes by identifying gaps in the empirical literature with regard to decision making within care homes.

Chapter 3 presents the methodology for the study. This chapter begins by discussing the research paradigm along with the choice of grounded theory methodology and a case study framework. The chapter continues with the method, starting with the selection of a care home and then the ethical considerations. It presents the data collection methods and then the data analysis process is described in detail. The trustworthiness and rigour of the study is then explored using Shenton's (2004) framework for assessing qualitative research.

The findings are reported in three chapters. Chapter 4 begins by describing the case study site along with information about the residents and staff in the home and the participating residents, relatives and staff. It discusses the types of decisions that were made in the home. Three categories of decisions were identified, everyday, infrequent and advance decisions. These categories were not in the order of importance to participants but were generated from analysis of the data.

Chapter 5 reports first on participant perceptions on what constitutes a decision. It then concentrates on the first of two central phenomena reported: that of resident as decision maker. Strauss and Corbin's (1998) paradigm model was employed to determine the central phenomena. The intervening factors identified in the paradigm model are discussed. These include resident and staff characteristics and actions as well as relative's involvement. It considers the home's routines, systems and policies, staff numbers, fear of risk and how these can impact on residents' opportunity to decide for themselves. Advance decisions are discussed and their importance to the different groups of participants are considered.

Chapter 6 focuses on the second of the central phenomena: others deciding for resident. These findings are organised within the three groups who were perceived to be making decisions for residents, staff, relatives and doctors. It considers how these actors made decisions and on what authority. The facilitators and barriers to relative involvement are also featured. The values underpinning decisions are explored.

Chapter 7 offers an interpretation and discussion of the findings. The first part of this chapter discusses the decision types. The chapter continues by exploring the findings in relation to advance decisions. It considers the discrepancy between the views on the value and importance of advance planning to the different groups of participants; residents, their relatives and staff. Crisis management when no advance decision has been made is also discussed.

The next section is structured using the paradigm model and the two central phenomena identified. It reports on the causal factors and the context, the intervening factors and the strategies employed by residents to make their own decisions and the strategies of others which enabled or restricted them. The consequences are considered throughout the discussion.

The next part of this chapter examines whether the discourse on values present in policy and professional guidance was evident in practice. It is considered whether or how participants understand and use the terms autonomy and dignity, the two key values most prevalent in the discourse, in interviews and conversations. The relevance of the concepts to everyday practice is discussed, as are the barriers to operationalising the concepts.

The chapter concludes with a discussion of, on the one hand, concepts of autonomy and choice for residents and on the other concepts of utility, of needing to run the home efficiently and within budget. Issues such as dissonance in stated values and practice by staff are discussed. Finally, the alternative concept to the oft referred to autonomy and dignity, solidarity is considered in relation to this study. This is a term which has recently entered the bioethical discourse and has the possibility to include all interested people in the care home.

Chapter 8 concludes the thesis by presenting the most salient findings and identifying the new knowledge that this study adds. It presents the implications and includes recommendations for policy, research and education and practice.

Chapter 2

The Empirical Literature on Decision Making in UK Care Homes

2.1 Introduction

This chapter provides a review of the empirical literature. It examines the evidence from empirical studies investigating aspects of choice and decision making in UK care homes for older people. The scope of the literature search was guided by the research aims and questions which are specified in the first chapter, section 1.3.

2.2 Timing of the Empirical Literature Review

The original work on grounded theory by Glaser and Strauss (1967) suggested that literature should not be reviewed before the commencement of data collection and Glaser (1992) later reiterates this view. This is to avoid the possibility of forcing the data through preconceptions established through extensive knowledge of the subject area (McGhee, Marland and Atkinson 2007). It is impossible for a researcher to be entirely naïve at the start of the research for several reasons. First, the researcher will have some knowledge and interest in the topic before selecting it as the theme for their research. Further, it is necessary to explore previous work on the topic to ensure there is potential for it to generate new knowledge and also to satisfy the ethics committee of the rationale behind the study (McGhee, Marland and Atkinson 2007).

There are some differences of opinion in later writing between Strauss and Corbin (1998) and Glaser (1992) on the best timing for the literature review. The former believed that reviewing the literature early in a study is necessary as it can stimulate questions and theoretical sensitivity, directing theoretical sampling while providing secondary data sources and supplementary validity. The latter believed that the literature must not be explored until codes and categories have begun to emerge as this will encourage theory which is genuinely grounded in the data and not emerging from preconceptions.

I had some knowledge of the literature in the subject area due to a dissertation for a previous degree. I conducted some exploration of the literature in the topic area to ensure its appropriateness for a PhD in that there was room to generate new knowledge. Further,

the study required review by an NHS research ethics committee and I needed to write a protocol with background to the study. I did however decide not to conduct an extensive review of the literature prior to commencement of data collection and initial analysis in order to adhere to the grounded theory methodology. The review was an iterative process where the data and initial analysis took me to certain literature, this led towards new ideas in the analysis of the data. This back and forth process had advantages over an initial literature review which would only be guided by theory and the developing research questions rather than by the data already collected.

2.3 The aim of the literature review

The aim of the literature review was to identify and critically analyse the published empirical work addressing aspects of the study questions presented below.

1. What decisions are made in care homes?
2. Who makes the decisions and with what authority and/or responsibility?
3. What are the barriers and facilitators for residents to making their own decisions and what factors influence relatives' involvement?
4. To what extent is the policy and public discourse of values in decision making reflected in the practice of staff?

2.4 Search Strategy

For the literature search (Hart 2001) for empirical studies I decided to concentrate only on studies published after 2nd October 2000. This is the date that the Human Rights Act (1998) came into force in the UK. The codification of this legislation was a fundamental change to the rights of people in the UK that could have an impact on the care of older people in care homes. Further, the year 2000 saw the Care Standards Act in England and Wales, 2001 the Regulation of Care (Scotland) Act and Health and Personal Social Services Act (Northern Ireland) which changed the way that care homes were regulated and introduced National Minimum Standards. It is likely that the introduction of these Acts encouraged care home managers to consider whether their practice was in line with the new law.

Due to the importance of the context within which a care home is situated I decided that only studies carried out in the UK would be included. There are significant differences relating to culture and systems between different countries. Although there are some differences in how health and social care are funded in England, Scotland, Wales and Northern Ireland and differences in the law, the systems are comparable (Bell and Bowes 2006), while many other countries have very different methods of funding and diverse laws which can have significant impact on the culture within care homes.

A search was conducted on these databases: CINAHL, Medline, British Nursing Index and the Cochrane Database. Snowball techniques (see Greenhalgh and Peacock 2005) were also used as the references from included studies and the later papers that had referenced them were considered.

Search terms used were, decision, choice, autonomy, care homes, nursing homes, long term care, residential care, older people, elderly, elders, old, dementia.

Inclusion criteria

- Empirical studies
- In a care home setting, whether residential or nursing home, in the UK
- Related to choice, decisions or autonomy
- Related to older people (either the use of the terms older people, elderly etc. or over 60)
- Published between October 2000 and August 2011

Exclusion criteria

- Not in a long term care setting
- Related to hospital discharge or the process of entering residential care
- Not applying to older people (the study did not apply to care homes for older people or included people under 60)
- Not empirical
- Research on funding on an individual basis or on funding policies
- Research on the efficacy and application of medical treatments
- Studies conducted outside the UK

- Published before October 2000 or after August 2011

1458 abstracts were screened. Sixteen studies were found to fulfil the inclusion criteria and full papers retrieved.

The quality of qualitative studies, and the qualitative components of those using more than one method, have been considered using the criteria suggested by Dixon-Woods et al (2004). Table A (appendix A) indicates whether the studies met each of the criteria specified by Dixon-Woods et al (2004). Three of the studies met the standards for all the criteria, two of these used both qualitative and quantitative methods with the other studies either having significant limitations or failing to report elements in sufficient detail for quality to be assessed. Using the framework from Dixon-Woods et al (2004), three of the studies were excluded (Bowers et al 2009; Winterburn 2009; Tak-Ying Shiu 2001) as I felt that the credibility of the findings could not be assessed and it was thus impossible to evaluate their contribution to knowledge.

The criteria set out by Petticrew and Roberts (2006) adapted from Crombie (1996) were used to assess the quality of questionnaire studies or parts of studies (Table B appendix B) and the criteria recommended by Thomas (2003) for the experimental designs (Table C, appendix C). None of these studies were excluded although Dunworth and Kirwan (2009) had significant limitations but due to its salience to this study it has been included.

This left 13 included studies. Overall most of the studies had limitations in the quality assessed against the criteria, mostly due to brevity of reporting. There was a lack of information in the published papers, thus, the findings have to be treated with caution. Despite these limitations these studies offer insight into decision making in care homes and how important making one's own decisions can be to residents. Consequently this study aimed to go some way to filling this gap in the literature on this topic which has been shown to be of importance to older residents of care homes.

A table detailing the aims and questions, methods and participants, findings, quality and limitations and the reference for each of the included studies can be found in Table D, appendix D.

2.5 Quality of the reviewed studies

A variety of methods were used in the included studies (Table D. appendix D). These included a longitudinal experimental design, a postal survey, questionnaires, structured interviews, semi-structured interviews, focus groups, observation, conversations and documentary analysis, some using a combination of these methods. Eight of the thirteen studies included residents with three including their relatives. The remainder included staff in care homes, managers, nurses, carers, activity coordinators and chefs and one included General Practitioners (GPs). Two of the studies included residents, their relatives and home staff as participants (Train et al 2005; Jones and Manthorpe 2002). The largest number of participants included 215 residents in structured interviews (Boyle 2004), the smallest was eight residents who took part in narrative interviews (Cook 2008).

There were three studies specifically examining choice and autonomy (Boyle 2004; Scott, Välimäki, Leino-Kilpi et al 2003; Jones and Manthorpe 2002). One of these (Jones and Manthorpe 2002) had limitations in its reporting and its findings need to be treated with caution. Five studies concentrated on specific issues, two on the end of life and advance care planning (Froggatt and Payne 2006 and Froggatt et al 2009), one on medication (Hughes and Goldie 2009), one on healthcare (Clarence-Smith 2009), the other on residents' involvement in the choice of décor (Knight, Haslam and Haslam 2010). The remaining four studies covered wider issues in care homes, people reconstructing their lives in care homes (Cook 2008), quality of life (Tester et al 2004), person centred approaches and communication (Wheeler and Oyedobe 2010) and the experiences of long term care for residents, their relatives and staff (Train et al 2005). Eight of the studies included residents, although only two studies appeared to include people who were cognitively impaired (Train et al 2005; Tester et al 2004) with Tester et al (2004) using some creative methods to ensure the voices of these care home residents could be heard.

There were no studies that specifically considered shared or collaborative decision making in care homes. Some of the studies considered how groups discussed decisions (Wheeler and Oyedobe 2010; Froggatt et al 2009) but this was not the main focus of any of the studies. Wheeler and Oyedobe (2010); Clarence-Smith (2009); Froggatt et al (2009) and Froggatt and Payne (2006) examined decision making for residents who lacked capacity. There have been no studies in the UK published between 2000 and 2011 that directly considered decision making in care homes for older people from the perspectives of

residents, their friends and relatives and staff that did not exclude residents due to cognitive impairment (Train et al 2005 included all three groups and residents with dementia but focused on experiences of long term care rather than decision making). Further, there were no studies considering both the decisions and choices residents made and those that others made on their behalf.

2.6 Review of the empirical studies

There were four studies that concentrated on the residents' perspectives alone (Knight, Haslam and Haslam 2010; Cook 2008; Boyle 2004; Tester et al 2004). Three of these concentrated on decisions relating to care, activities, everyday life and routines (Cook 2008; Boyle 2004; Tester et al 2004). Cook (2008) and Tester et al (2004) also focused on more personal decisions such as buying additional care and personalising their own space. Knight, Haslam and Haslam's (2010) study was on empowering residents to choose the décor in the communal space of the home. One study (Clarence-Smith 2009) included only family care givers and was considering health care decisions. Two studies included residents and staff, (Hughes and Goldie 2009; Scott, Välimäki, Leino-Kilpi et al 2003). Scott, Välimäki, Leino-Kilpi et al (2003) included care and treatment decisions while Hughes and Goldie (2009) concentrated on medication. Two studies had residents, staff and carers as participants (Train et al 2005; Jones and Manthorpe 2002). Train et al (2005) focused on care, activities and personal possessions while Jones and Manthorpe (2002) included care, everyday life and routines as well as end of life decisions. The two studies focusing exclusively on end of life issues only included care home managers (Froggatt et al 2009; Froggatt and Payne 2006). Dunworth and Kirwan (2009) used vignettes given to staff about everyday care issues in their survey. Wheeler and Oyebode (2010) included direct care staff and considered decisions around care and activities.

The scope of the literature relating to decision making for older people in care homes enabled the exploration of a range of issues relevant to the research aims and questions. This review is structured using the research questions as headings (questions one and two have been discussed together as this fitted with the nature of the reviewed studies).

2.6.1 What decisions are made in care homes, who makes them, with what authority and/or responsibility?

All the studies discussed various choices and decisions addressed in care homes, although this was not their main aim. Decisions included; those relating to care and treatment, everyday routines and activities and the care home environment. The most commonly mentioned issue was about personal possessions and residents personalising their own space (Cook 2008; Train et al 2005; Boyle 2004; Tester et al 2004, Scott, Välimäki, Leino-Kilpi et al 2003; Jones and Manthorpe 2002). Also mentioned by a number of authors were choice of clothes (Boyle 2004, Tester et al 2004; Jones and Manthorpe 2002), level of privacy, (Dunworth and Kirwan 2009; Train et al 2005; Scott, Välimäki, Leino-Kilpi et al 2003; Jones and Manthorpe 2002), food and meal times, (Jones and Manthorpe 2002, Train et al 2005). Five, Wheeler and Oyeboode (2010); Dunworth and Kirwan (2009); Train et al (2005); Tester et al (2004) and Jones and Manthorpe (2002) mentioned activities and general delivery of care. Studies also considered, where to spend the day (Train et al 2005), management of continence (Tester et al 2004), times to have drinks (Train et al 2005), use of money (Cook 2008), daily routine (Cook 2008), times of getting up and bathing (Dunworth and Kirwan 2009; Train et al 2005; Boyle 2004) and seeing visitors (Cook 2008). Cook (2008) discussed a resident who paid for additional support to provide her with assistance to pursue meaningful activities. In relation to where to spend the day, Jones and Manthorpe (2002) found that some residents were uncomfortable with mixing with people with severe cognitive impairment as they felt they were looking at their own unattractive future. This raises the difficult issue of how much people with dementia should be segregated.

Hughes and Goldie (2009) concentrated on the prescription and administration of medication while Scott, Välimäki, Leino-Kilpi et al (2003) discussed pain relief. Scott, Välimäki, Leino-Kilpi et al (2003) included the issue of consent and choice in relation to examinations, tests and treatment. Clarence-Smith (2009) considered healthcare provision and the involvement family carers. Knight, Haslam and Haslam (2010) considered the effects of an intervention to empower residents to choose the décor of communal space in a care home. Wheeler and Oyeboode (2010) included decisions on medication and healthcare.

The two papers, Froggatt and Payne (2006) and Froggatt et al (2009) focused on end of life issues and around advance care planning. Jones and Manthorpe (2002) and Clarence-Smith (2009) also included end of life decisions amongst other issues.

Studies identified the type of things that residents wanted to choose and take control over as well as the situations where they were able to exert control over their lives (Cook 2008; Tester et al 2004; Jones and Manthorpe 2002). Tester et al (2004) found that residents could express their identity through their appearance and personal possessions and Jones and Manthorpe (2002) discovered that residents' relatives linked this to dignity and staff being caring. Cook (2008) found the importance for residents of personalising their own space to retain independence. Boyle (2004) reported that although some residents thought the clothes they wore were important, staff did not always offer them a choice and this was confirmed by Jones and Manthorpe (2002). Tester et al (2004) and Knight, Haslam and Haslam (2010) argued that residents' quality of life was improved when they could retain their sense of self through making choices and asserting control.

In a number of studies there was evidence of residents' desire to make decisions (Cook 2008; Train et al 2005; Boyle 2004; Tester et al 2004; Jones and Manthorpe 2002) and of the benefits to them of making decisions and choices, whether about their everyday life and care (Knight, Haslam and Haslam 2010; Train et al, 2005), or about less common decisions including end of life care (Clarence-Smith 2009; Froggatt et al 2009; Froggatt; Payne 2006; Jones and Manthorpe 2002). Further, there were studies which indicated that staff recognised the importance of allowing residents to have control over their lives (Knight, Haslam and Haslam 2010; Dunworth and Kirwan 2009; Froggatt et al 2009; Hughes and Goldie 2009; Jones and Manthorpe 2002) and noting that most residents, even those with dementia, can make some decisions even if they needed support to execute them (Wheeler and Oyebode 2010; Train et al 2005; Tester et al 2004). Train et al (2005) also found that residents with a range of severity of dementia were able to verbalise choices and be understood.

However, in spite of this it was noted that staff did not always give residents the opportunity to make choices for themselves (Boyle 2010; Wheeler and Oyedobe 2010; Dunworth and Kirwan 2009; Hughes and Goldie 2009, Boyle 2004; Scott, Välimäki, Leino-Kilpi et al 2003). Cook (2008) found that staff were not always aware how residents were taking action to control their lives and this led to staff unintentionally undermining

residents' efforts. She also pointed out that although residents who were able to make decisions and execute them had most control; with staff assistance, decisions could be enacted by those who were less able. Boyle (2004) noted that attendance at religious services was important to some residents but as they were unable to go without support this choice was unavailable to them. Cook (2008) identified a further level in which residents could be empowered through negotiation, identifying the way people could live in the home and methods to achieve these.

Staff were identified as decision makers even when residents could have made their own decisions, for example, when to bath (Boyle 2004). Boyle (2004 p217) found that residents were willing to cooperate with staff, either because they considered they had to "live by the rules", or because of a perceived staff shortage. Hughes and Goldie (2009) found staff and GPs were in control of the prescription and administration of medication. Many residents, even those with good cognitive function, had little knowledge of what medicines they were taking. Clarence-Smith (2009) found that healthcare decisions, for residents with dementia, appeared to be made by doctors and care home staff with little communication with the family. Further, staff made many of the decisions at the end of life. Froggatt and Payne (2006) noted that any systematic consultation with residents concerning their preferences about end of life was limited.

The studies provided limited information on the authority and/or responsibility by which others made decisions for residents. Most residents cooperated with staff or accepted that, with staff numbers being limited, it would be easier to accept a bath when offered (Boyle 2004). Similarly, Tester et al (2004) found that most residents accepted rules and timetables although loss of control did generate negative feelings. In such circumstances it could be inferred that staff were taking the authority as given when residents cooperated. Hughes and Goldie (2009) also reported that residents were compliant with taking medication and in the interests of safety their autonomy was, at times, overridden.

Boyle (2004) established that where choice was limited by staff, older people often viewed choice as unimportant, presumably leading to a cycle of fewer choices being demanded and offered. Dunworth and Kirwan (2009) found that staff would make decisions based on delivering good care and keeping residents safe, taking their authority from what they considered to be their duty. They found that staff had difficulty expressing what they

considered the ethical principles involved. Train et al (2005) also noted that staff considered resident safety to be sufficient authority to override their preferences.

Scott, Välimäki, Leino-Kilpi et al (2003) found residents satisfied with their opportunities to exercise autonomy. However, there was a perception by residents that they were given less choice than staff reported. Hughes and Goldie (2009) noted that not all residents were cognitively able to make decisions about their medication and that healthcare professionals needed to make decisions in their best interests.

As all residents in Clarence-Smith's (2009) study had dementia it was assumed that residents were not able to make their own decisions about their healthcare so these decisions were taken by staff and doctors based on necessity. She found that many relatives of residents with dementia were content to hand over responsibility for healthcare decisions to care home staff as they felt exhausted by the time their relative was admitted. However, many relatives then felt frustrated at the lack of information they received. Staff had been given the authority to decide but had taken this further and not kept relatives appropriately informed.

2.6.2 What are the barriers and facilitators for residents to making decisions on their own behalf and what factors influence relatives' involvement?

A number of barriers and facilitators to residents making their own decisions were identified in the studies. These included risk, communication, staff strategies, staff shortages, communal living and routines, resident characteristics and relative involvement. These are discussed below.

2.6.2.1 Risk

Train et al (2005) and Boyle (2004) identified the need to balance risks with residents' right to make choices, examples included residents wanting an early morning cup of tea in bed but staff feared the risk of them scalding themselves (Train et al 2005) and the need to be accompanied by staff when bathing to ensure safety (Boyle 2004). Hughes and Goldie (2009) noted that if residents were given control over administration of their medication this would pose a risk to their safety. The risk could be reduced if staff retained control and staff considered this to be in residents' best interests. Boyle (2004) noted that there were often blanket policies to avoid risk which took little note of the individual's ability or willingness to take risks. This was echoed by Hughes and Goldie (2009) where, although

healthcare professionals accepted that self-administration of medication would return some independence and control to residents. the logistical difficulties of running parallel systems of supervised and self administration led to a single supervised system. prioritising safety.

Jones and Manthorpe (2002) found that staff were more likely to consider systems and policies as relevant than residents and this may have added to staff's fear of risk. They found however, that many staff thought that the focus on systems and quality could detract from the service they could provide to residents.

Train et al (2005) reported some residents' quotes where they talked of what they were "allowed" to do and needing "permission". It appeared that this was due to staff's concerns about safety. As the only study that included community dwelling older people, Jones and Manthorpe (2002) found that these community dwellers considered. if they entered residential care, that it would be important to be able to prepare snacks and drinks. Jones and Manthorpe (2002) noted that these participants knew little about the culture of residential care and thus were unaware that the culture often led to staff action focusing on avoiding risk of harm.

Hughes and Goldie (2009) discovered that both nurses and GPs who participated in their study considered they needed control of prescribing and administering medication to ensure resident safety and the continuation of care. Healthcare professionals accepted that residents had a right to involvement in their care but the need for control often led to disempowerment.

Dunworth and Kirwin (2009) posed a question to elicit staff's willingness to take risks. They found staff confused in their thinking as they wanted to allow residents freedom to engage in pleasurable hobbies but feared for their safety. They found staff unable to distinguish between ethical principles and rules and procedures.

2.6.2.2 Communication

All studies considered communication an important issue affecting life in care homes. Wheeler and Oyeboode (2010) focused on person centred approaches and communication. They noted that opportunities for good communication between staff were sometimes missed due to role demarcation between registered nurses and care workers. Handovers.

where some grades of staff were excluded, were seen to compromise team building and the development of shared values and goals which could lead to optimal care.

All the studies including more than one group of participants noted there were differences in what was considered important by the different groups. All these studies made it clear that better communication could help mutual understanding between residents, their relatives and the staff. Many reported that not all of any given group had homogenous views about their situation. Jones and Manthorpe (2002) for example, noted diversity in what residents would want if they were ill. About half said they would like to be left alone, the other half wanting to be checked to make them feel safe, showing the need to gain understanding of individual preferences. Scott, Välimäki, Leino-Kilpi et al (2003) also noted that due to frailty and age some residents desired to be looked after, diminishing their need to retain autonomy. Jones and Manthorpe (2002) found that choice of food and meal times was valued by many but not all residents but they, along with Train et al (2005) found that staff believed that residents should be involved in choosing food and meal times. Jones and Manthorpe (2002) went as far as to conclude that the expectations of their different respondents make it difficult to establish harmony in the shared space of a care home.

Froggatt et al (2009) found communication between staff, residents and their relatives affected advance care planning. Some staff were uncomfortable with raising end of life issues. The authors also noted that there could be conflict between family members making it difficult to reach a consensus. The need for a common goal between health care professionals from within the home and outside and relatives was considered to be a major factor in implementing plans when the resident was no longer able to express their wishes. Clarence-Smith (2009) found relatives of people with dementia confused about who was responsible for end of life wishes and making decisions for those who lacked capacity. She identified considerable frustration and uncertainty amongst relatives about primary health care with a lack of opportunity to communicate with GPs and little information given to them by staff.

Wheeler and Oyeboode (2010) and Tester et al (2004) referred to the need for care staff to support residents in making choices and taking control. They found that to provide this support they needed to engage with residents whether they were using verbal or nonverbal communication. However, Tester et al (2004) showed that staff lacked time and

opportunity to do this. Scott, Välimäki, Leino-Kilpi et al (2003) found that there was a difference in perception of whether residents were informed about their care and treatment. A majority of nurses, but only 15% of residents, said that residents were fully informed. This suggested a problem of communication where a perception of giving and receiving information differs.

Tester et al (2004) used a variety of methods to enable residents to take part in their research. With this creativity they were able to include people with severe cognitive difficulties. Such methods can be used to maximise opportunities for residents to make choices in their everyday life. However, they also noted that communication could be impeded by speech and hearing problems as well as poor use of hearing-aids.

Overall the studies demonstrated the need to communicate with residents to assess their individual preferences with many studies finding that assumptions were made without adequate communication. Further, communication within the home between staff and between staff and relatives was shown to be important.

2.6.2.3 Staff strategies

An example of a staff strategy which benefited residents was found in Wheeler and Oyeboode (2010). They identified the inventiveness of some staff with one saying that anything could be made into an activity and this could be done during delivery of physical care. Staff engaging in this way found their jobs more satisfying than those who were more task oriented and reported having little time for communication.

Cook (2008) noted that residents made decisions but would often require assistance from others to enact them. She found that staff were not always aware of residents' attempts to control their lives but their collaboration in enacting residents' decisions was vital. Tester et al (2004) also noted that frailer residents depended on staff to assist them with their choices. Residents' quality of life was affected by the strategies staff adopted to understand what residents wanted and their assistance in enacting those decisions.

Wheeler and Oyeboode (2010) found some evidence of disempowerment and this was more pervasive where staff were task rather than person orientated. Some staff described the use of bribery with chocolates to persuade residents to comply, with some seeing their role as

mainly observation. They found that this approach led to staff rather than residents controlling decision making.

Train et al (2005) found that staff often had to deal with physical and verbal abuse (sometimes racial) from residents. Although it was reported that some staff had left because of this, others managed by not taking it personally, understanding that residents with dementia often had difficulty expressing themselves. They also found some, although far from all staff, understood that when relatives were difficult or excessively demanding that this was because they had previously had little support and were close to 'cracking up'. With this in mind they could help relatives to cope with their situation and "remove the problem" (Train et al 2005 p24).

2.6.2.4 Staff shortages

Boyle (2010) reported that residents' choices were restricted (e.g. when to bath) due to staff shortages although this was not necessarily acknowledged by staff. Understaffing was also identified by Hughes and Goldie (2009) as a barrier to allowing residents to make decisions about treatment options which was a time consuming process. Wheeler and Oyebode (2010) found that some staff became task orientated because they prioritised residents' physical needs and found little time for communicating with residents. Froggatt et al (2009) mentioned that, in some homes, lack of time could be a challenge to ascertaining residents' views on their end of life care. Cook (2008), although not explicitly discussing staff shortages, interviewed a resident who had purchased additional personal support to assist her in pursuing interests she considered fulfilling for which the care home staff did not have time.

2.6.2.5 Communal living and routines

Jones and Manthorpe (2002) established that most residents appeared to accept that their choices would be reduced due to the constraints of communal living. Hughes and Goldie (2009) found residents compliant with the regimes that involved treating all residents the same to enable staff to retain control over prescription and administration of medicines.

Train et al (2005) identified the need for more individualised activities. This conclusion came from residents, their relatives and staff who all felt that there was a paucity of activities laid on and the activities provided did not suit everyone. Tester et al (2004) also noted that communal activities were not to everyone's liking and more individual

activities would be more appropriate. Knight, Haslam and Haslam (2010) identified the positive effects of empowering residents in choosing the décor in their home, but this starts from the default position where the home's decoration, fixtures and fittings are not of residents' choosing.

In her study of the perceptions of older people, Boyle (2004) reported that residents in care homes felt they had more choice and autonomy than those receiving care in private households. She considered these findings surprising but noted that people living in care homes and those being cared for in private households often had their decisional autonomy constrained by staff or informal carers. However, she also noted that participants considered choice unimportant when constricted by staff or informal carers, so it could be the case that those in care homes actually received less choice but perceived more.

2.6.2.6 Residents' characteristics

Boyle (2010) found that the older people who participated in her study were not always willing to assert themselves, even when freedom to choose was available. She also accepted that physical or cognitive frailty affected decisional ability and this was particularly in evidence where people were dependent on others for assistance with enacting a choice. Train et al (2005) found that many residents had difficulty communicating their choices about their everyday life and care and these difficulties acted as barriers to residents making their own decisions.

Cook (2008) identified residents' strategies employed to maintain control over their lives. Tester et al (2004 p90) also noted that residents were "Asserting control and choices, making complaints and adapting their environment" in order to maintain a sense of self. Where they were unable to implement their choices they sought help from their family, friends or staff although this assistance was not universally offered, often because others were unaware of residents' decisions and the actions they took in their attempts at control.

Froggatt et al (2009 p334) found that residents' "willingness and physical, emotional and cognitive abilities" all affected whether they could engage in advance care planning. Communication problems, whether due to physical or cognitive causes, could make the process extremely challenging. Froggatt et al (2009) and Froggatt and Payne (2006) drew attention to the large number of people with dementia living in care homes who were

unable to make decisions regarding their preferences about end of life care. Froggatt et al (2009) suggested that post admission may be too late to have the discussion about preferences for the end of life.

2.6.2.7 Relative involvement in decision making

Relatives were shown to want and to have different levels of involvement in decision making around the care and treatment of residents. The majority of participants in Wheeler and Oyeboode's (2010) study said that information supplied by relatives was invaluable for care planning, however relative involvement was patchy. Residents' families often sought more involvement with decisions about their relatives' care with Train et al (2005) noting that at times staff considered relatives to be unreasonably demanding. They found that relatives did not consider themselves to be equal partners in decisions made about residents' care. Train et al (2005) identified the need to develop partnerships between staff, residents and those close to them. The need to improve communication was found to be of great importance to achieve satisfaction for all parties. Clarence-Smith (2009) found that family carers had little information about their relatives' healthcare leaving them feeling discontent. However, some family carers felt relief that someone else could take on this responsibility after a difficult time prior to admission to a care home. A member of staff in Wheeler and Oyeboode's (2010) study believed that relatives did not get involved when they were satisfied with the care.

In relation to end of life and advance care planning, Froggatt (2009) identified family issues as one of the challenges managers faced. Family members were not always available or willing to be involved in advance care planning. Family dynamics could also be an issue, with family members disagreeing about the appropriate course of action.

2.6.3 To what extent is the policy and public discourse of values for care reflected in the practices of staff?

Autonomy was mentioned in five studies (Knight, Haslam and Haslam 2010; Train et al 2005; Boyle 2004; Tester et al 2004; Scott, Välimäki, Leino-Kilpi et al 2003), with only one mentioning dignity (Train et al 2005).

Boyle (2004) concentrated on older people's perception of the choice and control they had over their lives, suggesting this was indicative of decisional autonomy. They gathered qualitative data to explore the extent that participants exercised or experienced restrictions

to their autonomy. Although the findings generally indicated care home residents were satisfied with their level of choice and control, there was evidence that choices could be limited and residents' preferences overruled.

Dunworth and Kirwan (2009) found that the care home staff who participated in their study had difficulty articulating, or even recognising ethical dilemmas in their everyday work. The responses to the survey questions indicated conflict between the desire to allow residents to exercise their autonomy and the need to deliver good care and keep the resident safe. It appeared that in principle the staff strongly believed in residents' autonomy and right to self determination but in practice they were more pragmatic and prioritised a 'duty of care'. The authors saw this as deontological in theory but utilitarian in practice.

This conflict between recognising the value of autonomy and independence to residents and the need to retain control is identified by Hughes and Goldie (2009). As with Dunworth and Kirwan (2009) the utility of using control to ensure safety and deliver treatment overrides the recognition that autonomy is an important value. Dunworth and Kirwan (2009) link autonomy with deontology as though they were analogous, which is a simplification of complex philosophical theory. Scott, Välimäki, Leino-Kilpi et al (2003), who identified autonomy as one of the concepts as an important element in supporting patient choice and rights, found that staff considered that they offered information and decision making opportunities to residents far more than did residents themselves. This suggested that staff held different views on patients' needs and the measures necessary to respect patients' wishes and support their autonomy.

Autonomy is only mentioned briefly by Train et al (2005), in a more lengthy dialogue regarding choice. They found that residents had a strong need for choice and suggested that this is the same as a need for autonomy. Tester et al (2004), although their study included residents with significant cognitive impairment, considered that autonomy was important to their quality of life. They placed autonomy at the opposite end of the spectrum to loss of control, perhaps explaining what they perceived autonomy to be. This type of autonomy, although seen as important, was not always in evidence.

Knight, Haslam and Haslam (2010) concentrated on empowering residents and considered citizenship which is important in the concept of autonomy. They confirmed their

hypothesis that this type of empowerment, choosing décor for the home's communal areas, could provide a series of benefits to residents, thus establishing that putting the dialogue on autonomy into practice could enhance residents' lives. In most homes this type of empowerment was absent with management making decisions about the home's décor

Train et al (2005) used the term dignity without any clear explanation of what they considered it to mean, although it does appear to be closely linked to choice in the text. The study quotes a member of staff saying "Privacy and dignity is an aspect we really think about..." (Train et al 2005 p122).

Interestingly, Jones and Manthorpe (2002) focused on setting standards which is an area where the terms dignity and autonomy abide, but they did not use either term in their paper, neither did they report that participants used them. Dying with dignity is also an oft used term, but this was also absent from the two papers on end of life planning, (Froggatt et al 2009 and Froggatt and Payne 2006).

2.7 Autonomy and dignity in policy and legislation

The final research question asks; To what extent is the policy and public discourse of values for care reflected in the practice of staff? The policy and legislation that promote respect for autonomy and dignity in the care of older people is now discussed. The reasons that the key values of autonomy and dignity have been the focus is discussed in chapter 7, 7.3.

Both autonomy and dignity and the need to offer choice are much discussed in government policy. The language of rights is used in relation to the need to respect people and their choices (DoH 2010a). The right to make one's decisions and choices is supported by the principle of autonomy. The Government White Paper "Equity and Excellence: Liberating the NHS" (DoH 2010b p3) used the phrase "no decision about me without me". It aimed at promoting choice and control for all users of the NHS and shared decisions between clinicians and users. The influential charity, the Social Care Institute for Excellence (2010), in its widely publicised Dignity Campaign, emphasised the importance of choice and control for users of social care services. Both the Dignity in Care Campaign

(DoH 2006a) and Dignity and Older Europeans (Nordenfelt 2009) funded by the European Commission, added to the kudos of the concept of ‘dignity’

The DoH (2010c) published risk guidance in relation to people with dementia addressing the value of allowing people to take risks as this will promote their autonomy and well-being. Not only does government policy promote, choice, autonomy and dignity but the law codifies these values (e.g. Mental Capacity Act (MCA) 2005, DoH 2001).

The most salient law to decision making in England and Wales is the Mental Capacity Act (MCA) (2005). Although not discussed here, the Adults with Incapacity (Scotland) Act 2000 enshrines similar values in Scotland, Northern Ireland is still dependent on common law in regard to adults who lack capacity. The MCA code of practice (2007 p15) stated that;

the Act’s starting point is to confirm in legislation that an adult...has full legal capacity to make decisions for themselves (the right to autonomy) unless it can be shown that they lack capacity to make a decision for themselves...

In this code, the right to autonomy is equated with the right to make one’s own decisions. The Act demonstrates the need to protect the person who lacks capacity to make decisions as they are potentially vulnerable to abuse, exploitation or neglect. A person living in a care home may have their autonomy compromised as they are dependent on others to provide care and persons with dementia may lack the capacity to make autonomous decisions. As will be discussed (chapter 7, 7.3.1.1), autonomy is considered a good thing so its relevance to the care home residents who are the subject of this study is important.

The MCA (2005) codified the legal right of individuals to make their own decision if they have capacity to do so. There is a further obligation on others to take “all practicable steps” before assessing an individual as unable to make a decision. Nor can a person be judged to lack capacity for a decision due to a condition. Consequently, there is a legal obligation on those caring for someone with dementia to support the person to make a decision on their own behalf and not to assume incapacity. Capacity is not necessarily analogous with autonomy. It is dependent on which conception of autonomy is considered (see chapter 7, 7.3.1) and capacity is based on the decision not the person. It can be useful to consider this as Grisso and Appelbaum (1998) did, as a balance between the level of risk and the person’s mental ability; the greater the risk a person wishes to take the higher

their mental ability needs to be. The MCA (2005) advocates the promotion of autonomy in those least able to maintain it themselves. Further, it encourages the consideration that many individuals with cognitive impairment can and should be allowed to make some decisions for themselves, even if they lack capacity to make other more complex decisions with serious consequences. These decisions may not be autonomous in some senses discussed in the philosophical literature (see chapter 7, 7.3.1) but may still have the advantage of respecting the person and their choices. The individual may still be the best judge of their own best interests and the opportunity to decide can promote self-esteem and feelings of well-being and help the person to be viewed in a more positive light (Dworkin 1988).

The Deprivation of Liberty Safeguards came into force in 2007 under the auspices of the MCA (2005). These have important implications for decision making in care homes. The DoH (2010c) emphasised that although restriction of liberty can be acceptable, deprivation of liberty of movement is unlawful unless authorised. It gave the example that it could amount to deprivation of liberty if a person loses his or her autonomy due to constant supervision and control.

The Human Rights Act (1998) is also a relevant law. Several of the Articles in the Act give people the right to be free to decide how they will live their lives. The Act was based on the Universal Declaration of Human Rights (United Nations 1948) which identified dignity as the basis of human rights, with Article 1 starting with the words, “All human beings are born free and equal in dignity and rights”.

The standards that care homes are required to meet are discussed in chapter 1, 1.1.7. The CQC (2010b) Essential standards of quality and safety, under the auspices of the Health and Social Care Act (2008) require that service users’ autonomy and dignity is promoted.

The use of the term ‘dignity’ is apparent in professional guidance. The importance placed on dignity is evident in the Nursing and Midwifery Council (NMC) Code (2008). It is addressed in its first statement “make the care of people your first concern, treating them as individuals and respecting their dignity”. The term dignity is also used in other codes of ethics for professionals engaged in health and social care (NASW 2008; ICN 2006; ANA 2001; BASW 2002). The NMC (2008) code does not explicitly mention autonomy but mentions advocacy, the need to collaborate with those in your care, responding to their

preferences and gaining consent. The term autonomy is used in the codes of professional ethics of BASW (2002) and ANA (2001).

2.8 Conclusion

This chapter has discussed the empirical literature on decision making conducted in UK care homes for older people between the years 2000 and 2011. A brief discourse on the topics of autonomy and dignity in policy and legislation follows. The empirical literature on the topic of decision making in care homes is limited. Some of the studies had methodological limitations and many were not fully reported making quality assessment problematic (See Tables A-D in appendices A-D).

While these studies provide some insights into various aspects of decision making in care homes, none have looked at:

1. The breadth of the types of decisions that make up the daily life in a care home,
2. The multi-perspectives of all key groups, residents (including those with cognitive impairment), their friends and relatives and staff of all grades on decision making and,
3. Have at the same time used an explicitly values based lens to examine these perspectives in all aspects of daily decision making in care homes to reflect on the implications for care practice.

This study aimed to address these gaps.

Chapter 3

Methodology

3.1 Introduction

This chapter will critically discuss the methodology and methods used in this investigation. The underlying epistemology and explanation for choosing grounded theory methodology are presented. Grounded theory is then discussed in relation to the way it has been used in this study. The study methods and the rationale for the use of a case study framework are included followed by details of the analysis process. The trustworthiness of the research is considered as are the ethical issues. A discussion on reflexivity concludes the chapter.

3.2 Research Paradigm

A paradigm can be described as a “set of assumptions about how we know the world and what we do when we conduct research” (Alexander et al 2008 p127). Alexander et al (2008) identified the sometimes strong distinction between the paradigms of positivism and interpretivism. The positivists follow a deductive approach similar to that used in the natural sciences (Hodkinson 2008). In relation to ontology, the assumptions on the nature of reality, the positivist believes in a single objective reality and that research data will contain tangible facts that can be measured. The positivist epistemology leads to the belief that the purpose of social research is the development of theories about the world which are both abstract and general. They normally test hypotheses seeking causation and predictability. Positivists usually rely on quantitative data, rejecting studies using small numbers of participants as they cannot guarantee representativeness and consequently are seen as ungeneralisable (Alexander et al 2008).

This is in contrast with the interpretative paradigm. Ontologically there is a difference in the belief regarding what should, or even can be the subject of social research.

Interpretivists believe that the world is socially constructed and take a constructivist approach to data. They do not accept the positivist’s view of a single reality thus research can only interpret what the researcher has seen. Interpretation comes first from the participant and, in the process of the research, there will be reinterpretation.

Epistemologically. (epistemology being the nature, sources and limits of what knowledge is and how it can be acquired, Klein 2005), interpretivists do not look for generalisation, believing that the findings from research can only generate “local, historically-contingent meaning” (Alexander et al 2008 p138). They tell stories after seeking explanations and understanding of the phenomenon under study.

This study drew on an interpretative paradigm to realise the study aims. Lewis-Beck, Bryman and Futing Liao (2004) pointed out that the interpretative paradigm incorporates a number of approaches with common ontological and epistemological assumptions as outlined above. The assumption is that social phenomena can only be studied when there is understanding of the social environment, where meaning has been interpreted as part of everyday life and interaction between individuals. The interpretive approach therefore requires the research method to focus on the everyday life of people in their own setting. It is characterised by focus on the emic perspective i.e. the inside views, meanings and interpretations of those participating in the research (Crotty 2003). Thus it is necessary for the researcher to go into the real world and explore the already interpreted phenomena.

3.2.1 A Qualitative Approach

The interpretative tradition requires the use of qualitative methods. Cresswell (1998 p15) defined qualitative research as,

an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem. The researcher builds a complex, holistic picture, analyzes words, reports detailed views of informants, and conducts the study in a natural setting.

The aims of this study were to explore decision making and the processes and values that underpin it (Chapter 1, 1.3). The starting point is not a hypothesis of how things are or ought to be, but a desire to find out what the experiences are of the human participants with a stake in the care home. This method was partly dictated by the lack of empirical studies which meant that an exploratory study was necessary due to the paucity of evidence from which to generate a hypothesis. Qualitative methodology allows exploration of the phenomenon in a natural setting, in this instance the care home. As Strauss and Corbin (1998) suggested, the reason for using qualitative methods relates to

the research problem. Where research attempts to understand the experiences of people and the meaning they place upon them, it is difficult if not impossible to study this with other more 'conventional research methods'. Bowling (2002) saw the advantage of qualitative research methods in situations where there is little pre-existing knowledge, the topic is complex and the researcher wishes to maximise the opportunity for exploration and inductive hypothesis generation. Further, the qualitative design allows a much greater degree of flexibility (Robson 2002). It remains possible to adapt the focus of research as it becomes clear what is considered most important to participants and how this might best be examined.

3.2.1.1 Choosing a Methodology

A number of research methodologies were considered for the purpose of realising the study aims. Lowenberg (1993) posited that ethnography, phenomenology and grounded theory all fall under the umbrella of the interpretive tradition and these were considered in turn.

Holloway and Wheeler (2010) observed, when using a qualitative approach the major research tool is the researcher. While observing and interacting with participants, she must decide what is important and what is not, what must be asked of who and how it should be asked. This is true for all three of the approaches mentioned above. As the ethnographer needs to be open to new insights, the phenomenologist avoids prejudgement, the grounded theorist puts aside their preconceptions and theoretical ideas. This is a challenge common to all of these methodologies. The researcher inevitably comes to their study with previous experience, knowledge, values and beliefs. As Dey (1999 p251) stated "There is a difference between an open mind and an empty head". Orland-Barack (2002) suggested that theoretical sensitivity is an important issue in qualitative research in general. She identified the need to consider how the researcher's theoretical sensitivity influences all elements of the research process and the effect it has on interpretations and claims that are made. Consequently, reflexivity is an essential component in all qualitative research.

The key area where grounded theory differs from both ethnography and phenomenology is in the final product. Ethnography's aim is to describe and interpret the culture or system under study, written as a narrative or as Cresswell (2002) suggest a storytelling approach which may be challenging to those in social science research and those with an interest in policy. A phenomenological study gives a rich description of the phenomenon and looks

for common meaning placed upon it by participants in the study. The intention is for the reader to experience the phenomenon vicariously from the perspective of the participant. Morse and Field (1995) believed that although phenomenologists do not consider themselves to be theorists they link data to theory based on reflections on the theoretical literature. The final product of a grounded theory approach is the theory which is developed, grounded in the data without forcing the data to fit into pre-existing theory.

3.3 A Grounded theory approach using a case study framework

After considering these three methodologies I chose grounded theory because it most closely matched the aims of the study in intention. The systematic strategies originally devised by Glaser and Strauss (1967) were to guide all phases of the study (Charmaz 2006). Charmaz pointed out that Glaser and Strauss invited readers to use their strategies flexibly and as she said, she and many others have done so. Thus I have adapted the original methodology guided by the writing of a number of authors including Strauss and Corbin (1990 & 1998), Charmaz (2006) and Dey (1999) but also to enable a match between the strategies used, the aims and the constraints of the study and to complement my own strengths. The ultimate aim was to build theory by interacting with the data, using constant comparison and interrogating the data (Robson 2002). Using grounded theory the findings could be taken beyond description onto theory development.

The methodology known as grounded theory today was developed by Glaser and Strauss (1967) to add rigour to qualitative methods and to develop theory. Charmaz (2006) suggested that Glaser and Strauss, through their original work with hospital staff about death and dying, developed systematic methodological strategies which could be used to explore a wide number of topics in the social sciences. With this they made the analytical process explicit for the first time, making guidelines for analysis accessible.

The aim of a grounded theory study is to develop theory around a situation or phenomenon. The methodology has roots in symbolic interactionism which focuses on the interactions between people and the way these affect behaviour and social roles (Holloway and Wheeler 2010). Strauss and Corbin (1990) referred to theoretical sensitivity which is present to different extents in researchers, dependent on their knowledge and experience of the topic under study. They suggested that a greater degree of theoretical sensitivity will help the researcher with the analysis of the data. However, the researcher still needs to

ground the findings firmly in the data, as Glaser (1992) emphasised, they need to look for emerging theory rather than forcing the data to fit preconceived ideas.

Dey (2004) suggested that, due to differing perspectives between Glaser and Strauss in later years, further interpretations of grounded theory by themselves and other researchers, meant there is no unified methodology which can be described as grounded theory. The two perspectives are sometimes described as Straussian and Glaserian grounded theory.

The Straussian school takes strong influences from the pragmatist/interactionist perspective (Corbin 2009). Corbin (2009) believed that there are multiple realities and the research process must take into account multiple viewpoints. The focus of studies is not concrete events but the meanings put upon them, individuals' responses and the context of events are what are important to the researcher. Strauss and Corbin (1998) considered the importance of asking questions as an analytical device. Glaserian grounded theory challenges the use of a research question rather than following a core category. Glaser is also critical of the use of "pet codes" which are then applied to subsequent data, imposing framework onto data. Further, he put considerable emphasis on the need for objectivity from the researcher, reflecting his positivist background and the belief that there is an objective reality and the role of the researcher is to find it rather than interpreting multiple realities. Glaser considered that his later writings did not change from the original work conducted with Strauss (Noeragen Stern 2009). The work of Strauss and Corbin (2009) was developed to help the novice researcher using the methodology to understand what it involved, an evolution which Glaser wrote, bore little resemblance to the original work (Dey 2007; Glaser 1992).

Charmaz (2007) accepted the invitation from Glaser and Strauss's (1967) to use grounded theory flexibly, adapting the strategies in her own way. Her approach is constructivist, challenging the early work of Glaser and Strauss. She does not consider there to be a theory to "discover" but that phenomena must be interpreted by researchers, taking into account the participant's world view. After this interpretation of the studied world, theory can be constructed.

Grounded theory guides a qualitative research project from its inception to writing up (Dey 2004). Charmaz (2006) defined the components of grounded theory methodology as; simultaneous data collection and analysis; constructing analytical codes and categories

from data rather than from an established hypothesis; using constant comparison at each stage of the analysis; advancing theory development throughout data collection and analysis; using memos to elaborate categories, their properties and the relationship between them and to identify gaps; sampling not aimed at representing the population but rather at theory development and finally reviewing the literature after analysis. Morse et al (2009) considered that grounded theory is a specific way of thinking about data rather than just a collection of strategies. However, the components laid out above provide the basis for those who use a methodology they describe as grounded theory.

I have found it difficult after this discussion to declare myself as a proponent of one specific type of grounded theory or paradigm. With advice from Charmaz (2006) I have adapted the methodology of a number of theorists (Charmaz 2006: Charmaz and Mitchell 2001; Dey 1993, 1999; Strauss and Corbin 1990, 1998; Glaser 1978, 1992, and 2007; Glaser and Strauss 1967). I have made considerable use of Strauss and Corbin's (1990) text which offers many practical suggestions and has helped me gain inspiration from my data by encouraging me to look at it in different ways. I consider myself an interpretivist and have shied away from the idea of "discovering" theory in the data, which to me suggests a single reality existing independently of the researcher. Instead I interpreted the data and developed theory whilst firmly grounding my findings in the data while constantly reflecting on how my position in the study was affecting the findings.

3.3.1 A Case Study

I chose a case study (Yin 2009) to realise the study aims. I considered this the most appropriate method as it enabled me to develop relationships with all the stakeholders in one home. This enhanced the quality and veracity of the data as participants learned to trust me and be more open rather than presenting only the face they would wish a stranger to see (see Goffman 1959). The case study enabled me to use multiple data collection methods and to gain an in depth understanding of the contextual factors existing around the phenomenon under investigation. As a lone researcher, personal involvement in one site with a specific group of people was an advantage. Studying several sites would have been difficult with my limited time and resources. As Yin (2009) stated a case study is particularly useful where boundaries between the phenomenon under study and the context are unclear and where there are more variables of interest than data points. Both applied in this study. By concentrating on one home I was able to build relationships with

three groups, residents, their visitors and staff. The method of interviewing and observing all three groups meant that a broad perspective of life in the home could be explored. Further, a deep understanding of the topics under study could be obtained. The balance between breadth and depth is an issue in any qualitative study. Breadth is needed to generate comparisons, while depth will ensure that the data is credible (Dey 1999). Breadth was enhanced with the variety of participant groups and the different data collection methods while depth was obtained through a lengthy engagement with the people involved in life in the home.

Gerring (2007 p19) defined a case as “a spatially delimited phenomenon (a unit) observed at a single point in time or over some period of time”. A case study is described as an intensive study of a single case with at least part of its purpose being to shed light on a larger number of such cases (this is not considered a requirement by many other authors, Denzin and Lincoln, 2008). As this was a study of a single care home, spatially delimited, over a period of approximately one year and was designed to explore decision making, a phenomenon, and one of its aims was to consider the implications for practice in care homes more generally, this fits the definition by Gerring (2007) of a case study.

The case study has many facets, e.g “historical, cultural, physical, social, political, economic, ethical and aesthetic” (Denzin and Lincoln 2008 p127). They are complex but each component is worthy of exploration as any phenomenon is situational and cannot be understood outside its contexts.

Denzin and Lincoln (2008 p125) noted that the researcher in a case study will be searching for what is common and what is particular about the case drawing from,

1. the nature of the case, particularly its activity and functioning;
2. its historical background;
3. its physical setting;
4. other contexts, such as economic, political, legal and aesthetic;
5. other cases through which this case is recognised; and
6. those informants through whom the case can be known.

This information is best drawn from a variety of sources and methods, the triangulation of which will give credibility to both the description and the interpretation of the case

throughout the study (Denzin and Lincoln 2008). Consequently, in this study data were obtained from different groups of participants, residents, their relatives and friends and staff, including managers, registered nurses and care workers. Further, a number of methods were employed to collect data, namely, interviews, informal conversations, observation and analysis of written documentation.

The advantage of a case study is that it can capture an exact and very detailed picture of the phenomenon under study without the need of comparison with other cases (Flick 2009). Blaikie (2010) stated that one criticism is that they are difficult to generalise from. He suggested that if we choose a case which is typical this may be easier. However, he agreed that in most case studies it may be difficult to establish what is typical. With a care home this was certainly the situation. A care home could be selected on its location, type of ownership, whether it provides nursing care, its size, whether it is purpose built or what specialist care it offers. However, until the research is well underway, little will be known about the characteristics of residents and staff and how they interact, the type and frequency of visitors and their involvement, the policies and practices of management, to consider only a few important issues. Thus it is impossible to know whether a home is typical without conducting the research in many homes. With this in mind Blaikie (2010) suggested that it is vital to give enough information to the reader of the research to know whether the findings are applicable to their situation. The relatability rather than generalisability is important and enough thick description (see chapter 4, 4.2) will allow the potential user of the research to make an appropriate judgement.

Flick (2009) observed that a disadvantage of the case study can be the difficulty of integrating the various perspectives on the case. This was so where the information gleaned from residents, their friends and relatives and the staff as well as from other sources, observation and documentation were taken into account. However, this very disadvantage was also an advantage in that it gave depth and breadth that enabled confidence in the findings as each perspective could challenge ideas drawn from other parts of the data.

Blaikie (2010) noted that a case study is neither a research design nor is it a method of data collection. It is a method of data selection and as it has been used in a grounded theory study here it has been used for purposive sampling. Further, Blaikie (2010) posited that case studies can play a major role in theory development which was

another reason this design was appropriate to this study. The data collection process is explained below.

3.4 Method

3.4.1 Selection of a care home

Care homes are diverse but when selecting a care home I wanted to approach homes with similar characteristics to many other homes. Thus I considered the type of ownership, the number of homes the provider owned or leased, the number of places and whether nursing or only social care was provided. According to the Office of Fair Trading (OFT) (2005) the majority of care homes, about 75%, were in the “for profit” sector with about 15% run by voluntary organisations and the remaining 10% under Local Authority management. Approximately half of care homes were run by single home providers, with about a further third run by major providers (OFT 2005), St Bernadette’s was between these with the owners providing four homes. The average number of places in care home is 36 (Laing and Buisson 2010a). The OFT (2005) stated that 39% of place in care homes provide nursing care while 61% provide only social care. Eight homes for older people in the city borough where I was to undertake my research were privately owned and provided places for residents some of whom received nursing care while others received only social care. The three smallest homes were approached in the first instance as they had closer to average number of places and most homes in the borough were larger. All three managers agreed to meet with me to discuss the research. I met with the manager of St Bernadette’s who agreed that the research could be conducted within the home. This was the smallest home with 39 places with approximately half offering care with nursing, the other half only social care. This smaller number of residents also appeared ideal as I would have the opportunity to develop relationships with all residents, staff and visitors which would be more difficult in a larger home. The residents had a range of physical and mental capacities. These factors all pointed to this being a suitable environment for the study. Consequently, I arranged to conduct the research in St Bernadette’s.

3.4.2 Ethical Considerations

A number of ethical issues were identified. These were: the process of consent, the inclusion of individuals who lacked capacity to consent to participate or had fluctuating capacity, confidentiality and anonymity, the possibility of causing distress to participants

and the dissemination of the study findings to participants and professionals working in care and the general public. These issues are discussed below.

As reported in Iliffe et al (2009) over half of people with dementia are undiagnosed and about 70% of people in care homes were said to have dementia (POST 2006). Thus, many of the residents in St Bernadette's care home could be expected to have dementia whether diagnosed or not although as the MCA (2005) states as one of its principles, all participants were approached with the assumption that they had capacity unless established otherwise. All residents, even those with no cognitive impairment, are potentially vulnerable due to their dependence on others to provide care. Vulnerability is a poorly defined term and the phrase "a vulnerable older person" is a label without clarity. Clough (2010) of Age Concern, suggested that it is used to mean at risk, or with inadequate safeguards. He considered vulnerability to relate to a category of people at risk, an environment or a situation or event. Richards and Schwartz (2002) argued that a power imbalance in the relationship between researchers and their participants is inevitable. This imbalance can only be increased when participants are vulnerable, particularly if they have cognitive impairment. The literature has shown for some time that older people can usefully voice their opinions about their care and the lives they live in a care home (e.g. Raynes 1998). However, the inclusion of older people with dementia provides some additional challenges which needed consideration.

Historically people with dementia have often been excluded from research not allowing their voices to be heard (Dewing 2002 and Hubbard, Downs and Tester 2003). This can be explained in two ways. The first, that persons with dementia would be unable to speak for themselves, the other that their cognitive impairment leads to a vulnerability which means that it would be unethical to include them in research. With the view that all persons with dementia needed protection, proxies were used to try to understand the perspective of the person with dementia (Hellstöm et al 2007). The use of proxy accounts has been challenged, e.g. Spector and Orrell (2006) who found that carers rated quality of life in care homes differently to the residents. The need to hear the voices of people with dementia is now recognised (Moore and Hollett 2003). There is an increasing amount of evidence that residents in care homes, even those with dementia, can express their opinions enabling their voices to be heard (e.g. Wheeler and Oyebode 2010; Train et al 2005; Tester et al 2004.). Sherratt, Soteriou and Evans (2007) argued that reduced capacity does not justify excluding people from research which could be important to them. For a

study such as this it was essential to get the views of residents, many of whom had cognitive impairment.

It is important that all research participants are protected from any exploitation or harm. Hubbard, Downs and Tester (2003) recognised the need for researchers to be sensitive to participants' emotional states. They suggested that the researcher has a responsibility to support anxious participants, not just to avoid adding to negative feelings. They recognised that this can be difficult but use a positive example of supporting a resident by explaining what is happening when they express uncertainty. They also explained how questioning can cause a participant some distress when it draws attention to their inability to answer a 'simple' question. Nevertheless, it is important that everyone has the opportunity to have their voices heard and not be discriminated against. McKeown et al (2010) suggested that there is a risk that people with dementia can lose their right to choose to participate in research due to overprotective gatekeepers. Such examples as these helped me consider how best to approach participants in a sensitive manner without excluding the perspectives of residents who may be anxious. This study had the advantage of being a case study so relationships could be developed with participants prior to their participation. Hubbard, Down and Tester (2003) suggested that the diversity of individuals with dementia means that the researcher needs a repertoire of strategies to enable ethical engagement with all their participants.

The MCA (2005) states that a person must not be deemed unable to make a decision until information is given to them in a way that is appropriate to their circumstances, e.g. using simple language. This can be difficult for the researcher presenting information to people with cognitive impairment when ethics committees dictate the way information sheets must be written (McKeown et al 2010; Hellstöm et al 2007). The one off consent, taken before research begins, where a participant with capacity is informed and voluntarily signs a consent form will comply with ethical guidelines. However, if consent is not revisited throughout the research this is not an ethical way to conduct research (Hubbard, Downs and Tester 2003). In this study, consent has been treated as a process with the work of Dewing (2002) and McKeown et al (2010) used to guide the procedure.

It was necessary to assess which of the residents had capacity to consent. Capacity was assumed in the first instance but where there was doubt assessment followed. This was in consultation with staff in the care home, friends and relatives who visited residents and

with the researcher spending time talking to residents. Guidance was taken from the MCA (2005) Part 1(3) on capacity to make the decision on whether to participate in the study. Large print versions of the information sheets and consent forms were produced where necessary and information was given verbally as well as in writing to maximise the possibility of people being able to decide themselves.

Where people were unable to provide consent a relative or friend was nominated as a consultee and given full information about the study and asked to give assent in line with the MCA Code of Practice (2007). As I had access to the care home it was possible to talk to potential consultees about the study with the resident present. I was keen to establish whether the consultee, a friend or relative, would also like to participate in the research. Consequently, the resident was closely involved in the consent process even if they had difficulty understanding the written information sheet. Residents' assent was always sought and if they refused, whether verbally or through nonverbal behaviour I always withdrew. This applied not just during the initial consent but whenever I talked with the resident. Due to the time I spent in the care home I was able to develop relationships with residents which was useful to enable them, whether they had cognitive impairment or not, to feel comfortable in the research interviews and in being observed. Consent of all participants, residents, staff and friends and relatives was voluntary and they were all told that they could withdraw at any time.

Confidentiality and anonymity was maintained in relation to all the data collected. Participants were advised that any evidence of abuse, neglect or professional misconduct would result in breaching this confidence. Only the researcher and her supervisors had access to the raw data. Consent was obtained before any records (notes or care plans) were viewed by the researcher, and only relevant parts of the documentation were viewed. With consent, interviews were audio taped and transcribed. The data collection and storage met the requirements of the Data Protection Act (1998). Data was stored on password protected computers and in locked filing cabinets.

Feedback and dissemination are ethical issues in that respect for participants requires that, if they wish, they must be informed of the findings and the findings may have implications for practice which should be disseminated widely. Thus, a summary report will be written detailing the findings of the study and made available to all participants. A presentation of the study's findings will be offered to the care home where all staff, residents and their

friends and relatives will be invited to attend. Papers have been presented at conferences. Papers will also be submitted for publication in professional and peer reviewed journals. Throughout all the dissemination process confidentiality will be maintained and sobriquets used. In documents other than the one prepared for participants the care home has been anonymised and its name changed.

The study was reviewed by the National Hospital for Neurology & Neurosurgery & the Institute for Neurology Joint Research Ethics Committee and a favourable opinion was received (appendix E).

3.4.3 Data Collection

This section starts by explaining the intended sampling and data collection methods, continuing by discussing the process of data collection. The data analysis is then discussed followed by consideration of the trustworthiness and rigour of the study.

3.4.3.1 Intended Sample and data collection methods

Using a case study of a single care home, I intended to include as many of the residents, their friends and relatives and staff as possible. Yin (2009) suggested that the case study enables the collection of data from a number of sources. With this in mind, it was intended to use observations, interviews, informal conversations and care home documentation as data sources. The number of participants to be interviewed and the amount of time spent observing was not planned in advance in line with grounded theory methodology where data is collected until theoretical saturation is achieved (Strauss and Corbin 1990).

Immersion in the home was planned for a period of approximately a year. After permission had been granted to conduct my research in St Bernadette's, I was authorised to visit at any time and the manager introduced me to staff and residents. She went through the names of residents, telling me who she considered would be able to consent for themselves. She informed me of which residents had regular visitors who I could approach both as participants and, where the residents lacked capacity, to provide assent on behalf of the resident.

3.4.3.2 The Interviews

Interviews are a much used method in qualitative research and advice on how best to conduct them was taken from the literature (e.g. Bryman 2008). Further guidance was obtained in relation to conducting interviews with people with cognitive impairment from Hubbard, Downs and Tester (2003).

I started visiting the home and introducing myself to residents, staff and visitors, providing written and verbal information about the study. On my second visit I obtained consent from one resident, one relative and one member of staff, a registered nurse, to be interviewed for the study. On this and subsequent visits I requested consent for future interviews and to observe in the home. The interview topic guides were designed, initially consisting of a number of open ended questions to realise the study's aims (see appendix F). I aimed to reveal the decisions being made and the importance placed on them by participants as well as the process of decision making and the values underpinning them. Questions were included to ascertain what authority relatives and staff considered they had to make decisions. The interview topic guide was amended based on participants' responses. Details of this process are discussed below. Using these topic guides, the first resident, relative and staff member were interviewed.

These interviews were used to consider whether the interview topic guides were acceptable to participants and appropriate to realise the study's aims. This was done through careful holistic reading of the interview transcripts and identification of central themes. As well as assessing whether the research aims were addressed I considered whether there were other issues, important to the respondents, which should be included in future interviews. This process was also informed by some initial observation. Minor changes were then made to each of the topic guides. However, at this point no avenues were closed and some points that had been raised by interviewees were added to the guides.

I made the decision that it would be best to first concentrate on getting the perspective of residents and their relatives and friends, leaving staff interviews until later. This was because I felt that the interviews with staff would be enriched with the use of real life examples of decision making in the home derived from the interviews with residents and their relatives and friends. The next nine interviews were with four residents and five relatives, one of these being a joint interview with a resident and her daughter.

Theoretical participant sampling was facilitated through my knowledge of the people and incidents occurring in St Bernadette's. As many of the residents had cognitive impairment, interviewing without knowing them first would have been difficult. Developing relationships first made it possible to find ways of interviewing residents where they could feel comfortable. To enter a home, attempt an interview and swiftly leave may have had ethical implications as well as only obtaining superficial data.

Interviews lasted between 17 minutes and one hour. All participants consented to have their interviews audio recorded and transcribed. Interviews took place in the care home in a place where the interviewee was comfortable, this included the lounge, a meeting room, the nurses' office, residents' own rooms and the chapel. Demographic information was taken from participants and, with their permission, from residents' records.

3.4.3.3 Observations and informal conversations

Observation was used to provide greater depth and improve the veracity of the study. Hubbard, Down and Tester (2003) suggested that the use of observation is particularly important in research with people with dementia when verbal communication becomes more difficult. They saw the main advantage of this method as the opportunity to include the perspectives and experiences of people who would be unable to take part in a formal interview. Further, observation was used to triangulate the data along with interviews and examination of records. Observation guided interview questions and what to examine in records as well as who to interview. Conversely, interviews and records were used to indicate who, what, when and where to observe. Observations also gave a richer view of the context in which choices and decisions were made in the everyday world of those living, working and visiting the Home.

Observations were made of everyday life in the care home. What was to be observed was guided by the research aims and information given by participants in interviews. Observation was also to influence amendments to interview topic guides. Informal conversations were intended to guide both what was to be observed and what was asked at interviews. They also featured in clarification of situations that were observed and to discuss points raised in interviews. Informal conversations provided the opportunity to get to know people in the home and develop relationships to make data collection easier. For residents with dementia frequent informal conversations were more appropriate than the

use of formal interviews to collect data and in finding times when they were more able to engage.

On visits to the care home, while recruiting and interviewing I observed between 6.30 am and 11.30 pm. I observed the normal interactions, saw activities in the lounge, mealtimes and care giving in residents' rooms. I observed handovers both at the morning and evening change of shift. Further, I observed doctors' rounds, visits from speech and language therapists, chiropodists and the hairdresser. I had many informal conversations with residents, their visitors, visiting professionals and staff. Particular attention was paid to interactions between staff and residents where choices and decisions were being made. Field notes were taken and memos were written, noting where similarities and differences existed from the interview data and where further investigation was needed in interviews, conversations and observation.

3.4.3.4 Document review

A number of documents were examined within the care home to obtain information about decision making. The care home records, known as 'notes', of residents who had given consent, or a consultee had given assent, were analysed. Care plans were examined for the level of individuality and recorded resident and relative involvement in planning. In the notes, situations where decisions had to be made were sought. The home used the Gold Standards Framework for end of life care (National Gold Standards Framework Centre 2010). The paper work relating to this was also scrutinised. Demographic information, date of admission to the care home and the most recently recorded Mini-Mental State Examination (MMSE) scores were recorded. The MMSE was devised to assess the cognitive aspects of a patient's mental state (Folstein, Folstein and McHugh 1975). Tombaugh and McIntyre (1992) suggested that although it should not be used to diagnose dementia, it could be a useful screening tool as it "quantitatively assesses the severity of cognitive impairment and document cognitive changes occurring over time." (Tombaugh and McIntyre 1992 p922). Thomas (2010) noted that scores of 25-30 are considered 'normal', 21-24 mild, 10-20 moderate, <10 severe. The MMSE gave a perspective of the cognitive ability of residents which could be considered alongside the observation and knowledge of residents I obtained during my immersion in the life of the home. The form used to record resident information from notes, "Template for taking information from notes" can be seen in appendix G. Further, policy and procedure documents were

examined along with the Service Users' Guide with the aims of the research in mind. The Care Quality Commission latest report on the home was also viewed.

Field work, including interviews, informal conversations and observation were conducted between December 2009 and January 2011, visiting between one and four times a week.

3.4.4 Data Analysis Process

From the time interviews were commenced, analysis of transcriptions was started using the qualitative data analysis and research software Atlas ti to assist with the organisation of data. Prior to commencing formal analysis, each interview transcript was subjected to careful holistic reading. As Dey (1993 p30) argued, without breaking down the data in the analysis process the researcher would be dependent on "impression and intuitions". However, in his 2007 publication he admits to not being so sure about this position. He accepted that while something is gained in taking apart the data through analysis, something is lost. Sight of the big picture can disappear. Any system is more than a sum of its parts. It was often evident that if a sentence was taken out of context the meaning could be misinterpreted. This need to consider the bigger picture has to be balanced against the initial "impressions and intuitions" changing what can be found from the systematic analysis of the data and reducing the richness and depth of the findings, (Dey 2007). Strauss and Corbin (1990) reported in their chapter on open coding that they use the method of taking a whole interview and considering what is happening.

3.4.4.1 Memo Writing

Memo writing is an important part of the grounded theory methodology. It was used throughout the research process, beginning with writing about overall impressions, the data and codes and moving through more abstract levels to theoretical categories. Charmaz (2006) believed memo writing is crucial as it prompts the early analysis of data and codes. Memos were employed in a number of ways. I used them to reflect on interviews even before their transcription. I wrote down what seemed most important immediately after the interview, as well as impressions about the interviewee and our interaction. I was also observing and as I made field notes, these were interspersed with initial analysis in the form of memos. As I began open coding, memos helped to hold the fragmented data together and aided with constant comparison. My memos varied in length from a sentence or two to a page or more. As Corbin and Strauss (2008) noted the form they take is not what is important but the process of writing them. Writing memos helped

me throughout the research process in a number of ways including, considering the data and codes and what I thought was happening within them, what relationships existed between codes and what processes were taking place. I found this useful in deciding who to interview, what to ask them and who, what, where and when to observe as well as developing the analysis. Charmaz (2006) saw memo writing as a pivotal step between the data collection and the writing of the first draft. However, my memo writing continued through the writing of early drafts. I wrote down my thoughts and feelings which were notes to self and notes to supervisors and were not intended to be included in later versions of the thesis. All these types of memo writing helped to consolidate ideas about the data, suggesting times when it was necessary to take a step back and return to participants or earlier analysis and when to move forward to higher conceptual levels.

3.4.4.2 Open Coding

The first part of the process of analysis is open coding. Corbin and Strauss (1990 p61) described the process as “breaking down, examining, comparing, conceptualizing and categorizing data”. Line by line coding was performed, Charmaz (2006 p50) suggested this can be “an enormously useful tool”. Ideas are generated that would be missed through reading data using a more general thematic analysis. Further, she stated that this type of coding can be used to guide future analysis and the type of data to be collected, as important elements are identified and can be pursued. Codes were often taken from the exact words used by participants, known as *in vivo* codes (Strauss 1987), their purpose, to keep analysis close to data. This resulted in hundreds of codes, many used only once. I found that many were descriptive or concrete in nature, not taking into account context and consequently they felt largely meaningless. Constant comparison, as Charmaz (2006) pointed out, is the main method on which grounded theory depends. This sort of comparison was difficult when codes were often not being duplicated and were difficult to link. Although this did identify some areas worthy of pursuit, as Strauss and Corbin (1990) suggested it would, it did little to help the analytical process.

As this was proving problematic I had to find an alternative method of open coding. I felt I already had an overview of the interviews and their content. The process of reading interviews in their entirety and line by line coding helped me to identify key issues and gave me insight into the data. However, this did not solve how systematic analysis and open coding could be applied to the data in a meaningful fashion. While using line by line

coding and holistic reading to guide the direction of future data collection, I sought a more productive method of open coding.

Charmaz (2006) suggested an alternative method of open coding, incident by incident. She considers this a close cousin to line by line coding. She opined that line by line coding may not be amenable to concrete descriptions of mundane actions and behaviours and might not take account of the context and the actors. I considered that incident by incident might be restrictive, missing some elements of data which were important but could not be described as an incident. Consequently, I concluded that coding of 'meaningful chunks' of text would be more appropriate. This would be inclusive of all parts of the data where meaning could be found, often around incidents but also about thoughts, feelings and history. Each chunk was delineated by where a single idea started and finished. Although inevitably, I, as the one conducting the analysis, had to decide where the meaning lay, I constantly scrutinised the data, focusing on the participant's meaning. The length of each chunk varied considerably as large sections where an interviewee continued to talk about a topic could be coded as a single chunk, on other occasions a chunk was just a few words. Each chunk remained within its context which avoided misinterpretation of 'orphaned' words or lines. Codes frequently overlapped as normal dialogue is fluid and can flit between topics. Each interview was methodically examined with the research aims in mind and meaningful excerpts were identified and coded. Strauss and Corbin (1990 p77) contended that theoretical sensitivity will be enhanced if the data is interrogated using the questions, "Who? When? Where? What? How? How Much? and Why?". These questions were asked of the data whenever they were appropriate. Constant comparison then became easier and more meaningful. At this point I started developing the research questions although this process continued through much of the analysis.

Strauss and Corbin (1990 p95) suggested that everyone has their own "biases, assumptions, patterns of thinking and knowledge gained from experience and reading". They believed that this can lead to difficulty in finding what is significant in the data and block the progression from the descriptive to the theoretical. They recommended some techniques which can help overcome these problems. These were;

1. The flip-flop technique,
2. Systematic comparison of two or more phenomena,
3. Far-out comparisons and

4. Waving the red flag

The first is when a phenomenon is identified but is unclear. the flip-flop technique is employed turning the concept upside down and considering the polar opposite which can bring clarity to the original phenomenon. This was particularly useful where participants' responses were along a scale. Systematic comparison involves comparing different elements within a category. Far out comparison means comparing things which at first appear to have little relationship to each other but with careful consideration and questioning can illuminate features of each category that bear a resemblance, seeing them in a new way. Waving the red flag is about challenging what appears to be obvious. This helped me to challenge my preconceptions which were not based on the data. Strauss and Corbin (1990) suggested that the researcher should be sensitive to words like 'never', 'always', 'everyone knows' or 'there is no need for discussion' as there is a need for further investigation to avoid assumptions. All of these techniques were employed and proved useful at various times during my analysis.

Initially coding and constant comparison was performed separately for the three groups of participants, residents, friends and relatives and staff (including both care workers and registered nurses).

3.4.4.3 Focused Coding

Charmaz (2006) suggested that this is the next phase of coding. As an understanding of the data developed from open coding, coding became more selective and focused on the salient features that had been found in the data. These codes were often applied to larger segments of the data to reach a more conceptual level. As Charmaz (2006) explained, this was not a linear process and as ideas developed and I made decisions about the direction to take the analysis, I frequently returned to open coding in order to follow a new path. This back and forth in the coding process led to clarity of focus and started to illuminate what was most important in the data.

3.4.4.4 Axial Coding

Axial coding was then performed. Strauss and Corbin (1998 p123) defined axial coding as, "The process of relating categories to their subcategories, termed "axial" because coding occurs around the axis of the category, linking categories at the level of properties and dimensions". They saw the purpose of axial coding as to put back together the data

that was fractured during open coding. They accepted that many of the links between categories and subcategories will be identified during axial coding. Strauss and Corbin (1998) explained that a category is a phenomenon which is significant to a participant. It might be a problem, an event, a happening or another issue. The category, the phenomenon, explains what is happening while subcategories answer questions about the phenomenon, the when, where, who and why and the consequences. The linking of categories and subcategories takes place on a conceptual rather than a descriptive level.

Strauss and Corbin (1990) purported that, in axial coding, it is necessary to question whether there are relationships between categories. When relationships appear to exist a type of hypothesis is proposed which is then verified against the data. Part of the data might support the hypothesis while other parts may qualify it. They stated that this will add variation and depth to the researcher's understanding of the phenomenon, as she questions why the alternative or negative cases exist.

Strauss and Corbin (1990) have adopted the paradigm model to enable systematic thinking about the data and as an aid to linking them together in more complex ways.

Their simplified model is presented here:

- A) Causal conditions *leads to*
- B) The Phenomenon *taking place in*
- C) Context
- D) Intervening conditions *affect the phenomenon*
- E) Action/interaction strategies *are influenced by the phenomenon*
- F) Consequences *of the action/interaction*

The phenomenon is the central event or idea which relates to a set of actions/interactions. The causal conditions lead to the phenomenon. The context is the location in which the phenomenon and the actions/interactions around it take place. The intervening conditions might be described as the wider context including, culture, individual biography, time and space. Strauss and Corbin (1990 p104) contended that "Grounded theory is an action/interactional orientated method of theory building". Action/interaction is dynamic and purposeful, the failure to act or interact is equally important to understanding and there are always intervening factors which will affect the action/interaction. Consequences

describe the outcomes of the action/interaction and I noted that a consequence could be that previous actions/interactions could change future behaviours.

The paradigm model has been utilised during analysis to explain the findings and to open up new ideas. This was the point at which the analysis from the different groups of participants and the different data sources was merged. Two central phenomena were identified, one relating to the resident as decision maker the second, others decide for resident.

Although, as has already been mentioned, Strauss and Corbin (1999) opined that open and axial coding are distinct analytical processes they noted that in practice the researcher moves between the two. As this process progressed I was again drawn back to focused coding and at times to open coding to elucidate and sometimes challenge the direction of the analysis. I was constantly moving between the merely descriptive and the conceptual and through comparison I was linking categories. However, when I felt that open coding was complete, at least for a time and I was ready to move to axial coding, the shift provided new impetus for the analysis and new insights materialised.

3.4.4.5 Selective Coding

The final step in my analysis was selective coding. Dey (1999) described this as delimiting, whereby the central category or categories have been identified and coding can concentrate on this area. This was a particularly challenging part of the analysis as to follow core categories it was necessary to disregard others. This required confidence in my analytical ability that felt lacking. These difficult steps were facilitated by discussion with supervisors and colleagues about the way forward. The vocalisation and ability to explain my ideas helped clarify them in my own mind and developed the confidence I needed to take the analysis forward. After using Strauss and Corbin's (1990) paradigm model and the identification of central phenomena analysis focused on the components of this model.

The issue of theoretical saturation became relevant at this point. I needed to feel sure that the core categories were sufficiently developed and that little would be added to the conceptualisation by collecting more data or by further analysis. Dey (1999) had difficulty with the term theoretical saturation as it is impossible to know when it is reached as there may just be something to add in the next interview we conduct or the next section we code. He suggested theoretical sufficiency is a better term, avoiding making claims of

saturation that are impossible to substantiate. As I wrestled with this problem I considered the advice from Charmaz (2006) to remain open to what is happening in the field and to go back and code more data where necessary. I also returned to participants on a number of occasions to clarify my understanding and interpretation.

3.4.5 Trustworthiness and Rigour

Dixon-Woods et al (2004) noted both the importance and the difficulty of appraising qualitative research. However, if this type of research is to contribute to the knowledge base, criteria is necessary by which it can be judged. Shenton (2004) wrote about strategies for ensuring trustworthiness in qualitative research based on the criteria laid down by Guba (1981). The four criteria identified were credibility, transferability, dependability and confirmability.

3.4.5.1 Credibility

Similar to the positivists' concept of internal validity, credibility in qualitative research ensures that the study reflects reality. If the view that there are multiple realities is accepted (see Corbin 2009), a valid interpretation of the realities experienced by participants and researcher must be provided. Shenton (2004) suggested strategies that promote confidence in the credibility of the findings. The first is adoption of well established research methods as have been used here. The next is developing familiarity with the culture in which the research is conducted and Shenton (2004) opined that only those who will provide data willingly should be included, rapport built and respondents encouraged to be open and honest. The case study framework optimised this. Shenton (2004) recommended random sampling. I have used theoretical sampling as grounded theory methodology requires (Strauss and Corbin 1990), this has been discussed in section 3.4.3 above.

Triangulation of methods is considered useful as the strengths of one method can compensate for short comings in another (Shenton 2004). I have used interviews, observation and examination of records and included residents, their relatives and friends and staff, an additional triangulation.

Denzin and Lincoln (2008 p7) state that,

The combination of multiple methodological practices, empirical materials, perspectives, and observers in a single study is best understood, then, as a strategy that adds rigor, breadth, complexity, richness, and depth to an inquiry.

Shenton (2004) recognised the need for frequent debriefing sessions and peer scrutiny. My supervisors provided debriefing sessions and as Shenton (2004) recommended, facilitated discussion about alternative approaches. I have had peer scrutiny of my work (see appendix H). Shenton (2004) also valued reflection from the researcher especially around data analysis and the process of drawing conclusions. Reflexivity and reflection are discussed in section 3.4.6.

Member checking is considered to be important by Shenton (2004). Verbatim transcripts were not given to participants due to the possibility of participants feeling disempowered if they perceived themselves to be inarticulate or to have poor spoken English (Manias and Street 2001). However, I used an alternative approach to verify participants' perspectives by regularly returning to check I had interpreted them correctly utilising informal conversations.

Thick description of the case study site has been presented in chapter 4. This describes the location, people, events and situations. It also includes recording verbatim the experiences and perceptions of participants within the context (Holloway 1997). Lincoln and Guba (1985) purported that giving a sufficiently detailed description of phenomena will permit the reader to evaluate whether the study's conclusions are transferable to other people in different situations, settings or times. As recommended by Shenton (2004), the findings of this study have been related to previous literature in the field to explore the congruence between them (chapter 7).

3.4.5.2 Transferability

Shenton (2004) noted that transferability is a difficult issue in qualitative research as the findings are specific to the participants and environment. However, if the reader has sufficient information about the methods used, the participants and the environment, they will be able to assess whether the findings are relevant to their particular context. Blaikie (2010) used the term relatability which, with sufficient description, can be judged by the reader.

3.4.5.3 Dependability

Shenton (2004) equated dependability with the positivists' reliability. He accepted that it is not possible to replicate a qualitative study and expect to duplicate the results. Shenton (2004) saw a relationship between credibility and dependability, so using 'overlapping' methods (such as interviews and observation) may help to demonstrate both credibility and dependability. He considered it important for the researcher to report the study's design and implementation, details of how data were collected at a micro level and reflective appraisal. These issues have been incorporated into the writing of this thesis.

3.4.5.4 Confirmability

Confirmability corresponds with objectivity in the positivist research paradigm. Shenton (2004) saw confirmability as the need to ensure that the findings reflect the participants' experiences and ideas rather than the researcher's. He recommends triangulation to help reduce researcher bias. It is unclear how Shenton (2004) considered this reduces bias, but in my experience the use of data from a number of sources challenged my preconceived ideas and enabled me to see things from different perspectives.

3.4.6 Reflexivity

I have considered the importance of reflexivity throughout the research process. The researcher and her position are central to a qualitative research project, thus reflexivity is an essential part of the project. What reflexivity means, in a project such as this, is now discussed.

Finlay (2002 p532) defined reflexivity thus,

...thoughtful, conscious self-awareness. Reflexive analysis in research encompasses continual evaluation of subjective responses, intersubjective dynamics, and the research process itself. It involves a shift in our understanding of data collection from something objective that is accomplished through detached scrutiny of "what I know and how I know it" to recognising how we actively construct our knowledge.

Dowling (2006) discussed four forms of reflexivity. These were, "reflexivity aimed at sustaining objectivity" (Dowling 2006 p10), "epistemological reflexivity" (Dowling 2006 p11), "reflexivity from a critical standpoint" (Dowling 2006 p12) and "reflexivity from a feminist standpoint" (Dowling 2006 p13). The first aims to sustain objectivity by suspension of the biases and beliefs held by the researcher. This comes from the positivist tradition in that researchers separate themselves from the phenomenon under study. Finlay

(2002) argued persuasively that it is impossible for the researcher to have no impact on the research however much they consider and try to bracket their beliefs and biases. My epistemological position, which is discussed in section 3.2, demonstrates my belief that the researcher cannot be separated from some objective reality.

Epistemological reflexivity is important in any research project as the researcher considers their world view and how that has resulted in their choice of methodology and methods (Dowling 2006). This affects the research and its findings so cannot be ignored. As Baker, Wuest and Noerager Stern (1992) professed, grounded theorists do not put aside their past knowledge and beliefs but accept themselves as social actors in the world using their past experience and knowledge to guide them in gaining understanding of the processes under scrutiny. Grounded theory has included the idea of theoretical sensitivity and its importance in theory development from its foundation (Glaser and Strauss 1967). Strauss and Corbin (1990) identified three sources of this sensitivity, literature and professional and personal experience. They believed that, when applied appropriately, all these resources would help the researcher in their quest to understand that which they study.

Dowling (2006) also discussed the need for self exploration and understanding to allow openness to the perspectives of others. She referred to Turner (2003) where he used Gadamer's term 'Bildung' or openness to meaning, suggesting that this could only be achieved after careful consideration of the self and the beliefs and attitudes brought to the study.

Dowling (2006 p12) suggested that reflexivity from a critical standpoint is the process of examining the "political and social constructions that inform the research process". This holds relevance to all research regardless of its methodology. It can help to address some of a study's limitations, ethical and political issues and challenge veracity, adding to any study's validity (Dowling 2006).

The final type of reflexivity, addressed by Dowling (2006), is from a feminist standpoint. As this considered power differentials this has obvious relevance to this study which included participants who were potentially vulnerable (vulnerability is discussed in section 3.4.2) and thus at risk of being disempowered. Dowling (2006) suggested that feminist research embraces biases to enable sufficient reflexivity to enable the researcher to understand and interpret what is under investigation. She considered this to encourage

engagement rather than detachment in qualitative research. This develops a collaborative relationship, a partnership between researcher and participant where the researcher will use her own experiences and beliefs to draw out meaning. Dowling (2006) considered that keeping a distance from participants is difficult, for nurses particularly, and less objective engagement would be more authentic and help the study.

Dowling (2006) opined that reflexivity is not synonymous with reflection despite the words often being used interchangeably. She suggested seeing them as opposite ends of a continuum with reflection at one end being “thinking about” at a distance after the event. The other end is reflexivity which is “immediate, continuing, dynamic, and subjective self-awareness” (Dowling 2006 p533).

Thus, reflection and more importantly reflexivity have been central elements of all parts of this study, from its inception to the writing up process.

3.5 Conclusion

This chapter first discussed the methodology in this study and went on to describe the methods used. The ethical considerations, trustworthiness and rigour and the importance of reflexivity were also discussed. The following three chapters present the findings, chapter 4 describes the case study site and the participants and the types of decisions identified. Chapters 5 and 6 present the results first in relation to, resident as decision maker and latterly, others deciding for resident.

Chapter 4

The participants and decisions made

4.1 Introduction

This is the first of three findings chapters. It provides a description of the participants, residents, relatives and friends and staff. It briefly recaps on the analysis method which is described in detail in chapter 3. Its final purpose is to discuss the types of decisions that were identified during the study. The following two chapters present the two central phenomena firstly, resident as decision maker and secondly, others decide for resident.

4.2 The Case Study Site

St Bernadette's care home (not the real name, here on referred to as the Home) was owned by a private company in a large city in the South East of England, the company runs a total of four homes.

While the Home was, at the time of the research, a secular establishment, its history revealed its establishment as a religious home. The Home was partly converted but largely purpose built. It was originally a home for the physical and spiritual care of poor homeless girls. The property was given to an order of Roman Catholic nuns in the early twentieth century, at that time there were 12 rooms. Later it became a home for elderly ladies, mostly Irish, who had been in service and since retired. It later became a care home for older people with gentleman also being admitted. Most residents were of the Catholic faith but it was not a requirement for entry. In 1984 a large extension was built due to changes in the regulations for care homes. A further extension was built in 2000 and the home then offered nursing care. Throughout the time the home was run by the nuns, they lived in the convent attached to the home and provided 24 hour care. Due to financial difficulties and the nuns ageing and their numbers reducing, the home was sold into private ownership in 2006. This history was given by a resident of 24 years.

The Home had stated aims and quality standards in a number of documents for potential residents, relatives and staff. The aims stated in the Service Users Guide were, "To provide personal and nursing care, including Registered Nurse Care...to elderly people, of both sexes, over the age of 65...for long term, short term for convalescence and holiday

stays. To foster an atmosphere of care and support which both enables and encourages our residents to live as full, interesting and independent a lifestyle as possible with rules and regulations being kept to a minimum.” The Home’s quality policy stated that they were committed to providing quality services by “caring, competent well trained staff in a homely atmosphere. This will be achieved by:” staff development, recruiting staff who share the values of the home and providing resources ensuring effective training. They “...will provide services based upon consultation and assessment of residents’ needs. This will be achieved by: Listening to staff, residents and others with an interest in the home. Ensuring that assessments are made which balance risks and needs. Promoting a level of responsible risk-taking in daily living activity. The operation of an effective care planning system.” They will involve residents in the planning and review of services to meet their needs by “Enabling and empowering residents to influence the services provided...by giving each resident a real say in how services are delivered. Encouraging residents to become involved in all decisions that are likely to affect them, either now or in the long term.” They will consult people about satisfaction and suggestions for improvement, provide catering to meet residents’ expectations and inform residents about all matters which might affect their well being. Residents and staff will be afforded equality of opportunity, ensure that the home is a safe and secure place to live and offer a range of social activities to meet residents’ needs. (Information taken from the Service Users Guide).

At the time of the study the Home had 39 single rooms, seven with en suite facilities, on two floors. It had a dining room with seating for 20 residents beside the kitchen where meals were prepared by the regular chefs. There was a lounge on the ground floor with patio doors leading onto an enclosed, well kept garden to which the residents had access. During the summer months there was an awning enabling residents to sit outside, sheltered from direct sunshine. Residents could smoke in the garden. There was a small kitchen in which drinks were made for residents. There was a clinical room, a room which could be used for meetings and a laundry room where all the Home’s laundry was done including residents’ clothes. There was a chapel, built in 1990, and there was a Catholic Mass celebrated there each Sunday morning which residents and visitors could attend. The church was next door to the care home and there used to be a connecting door but this was closed when the home went into private ownership.

St Bernadette's was located close to local shops and bus routes and about $\frac{1}{4}$ mile from a railway station. It was on a main road but sitting back with a car park in front and there was little traffic noise inside the home. It was about two miles from a major teaching hospital which had an Accident and Emergency Department.

All residents were registered with the Home's GP practice, a GP routinely visited twice a week. A large number of other professionals came in to provide health and social care services when referred by Home staff or GPs. These included; speech and language therapists, chiropodists, the Home Enteral Nutrition Team, social workers, physiotherapists, hairdressers, palliative care nurses, occupational therapists, diabetic nurses, dieticians, tissue viability nurses, community psychiatrists, a dentist, a nurse facilitator for end of life care for people with dementia, and incontinence nurses. They also received support from the Local Authority's multi-disciplinary care home support team which assessed residents' needs, assisted with practice development and training from a wide variety of professionals on a number of topics.

The Home provided places for residents needing both residential and nursing care. It was registered for the categories, old age, not falling within other categories and physical disability. The most recent Care Quality Commission inspection had given the home an "adequate" rating (1), however they were inspected during the course of the research and a "good" rating (2) was awarded.

4.2.1 Demographics of residents

At the time the research commenced, there were 30 residents with an average age of 82.6 years (range 54-99). Twenty one were female and nine male. Three residents spoke very little English, one had Portuguese as her first language, one Italian, the other Goan. There were staff in the home who spoke Goan but no one who could speak Portuguese or Italian. One further resident did not have English as a first language. Five of the residents were Irish, one Scottish, two Indian, one Madeiran, one Italian and the remainder English. The average MMSE score was 18.5 (range 0-30). During the year prior to the research 20 residents died and two were transferred to other homes.

4.2.2 Staff details

There was a total of 45 staff employed in the Home. The average age was 35 (25-66). Fifteen were qualified nurses, the remainder care workers. Of the care workers ten were

qualified nurses in other countries but were not registered to practice as nurses in the UK. All the qualified nurses were trained in countries other than the UK including India, the Philippines and Jamaica. Ten of the staff had English as their first language. All the care staff had or were working towards NVQs, ten had completed NVQ 3.

4.3 Profile of Participants

4.3.1 Participating residents

The demographics of all the residents in the Home are given above. Twenty one of the residents agreed and were able to participate in the study. All of these were observed and engaged in informal conversations. Eleven consented, or where they lacked capacity, provided their assent to be formally interviewed. Seven of their relatives and one friend were interviewed; two residents were interviewed at the same time as their relative. The consent and assent process is discussed in the previous chapter in 3.4.2 and details of participating residents and their consent and assent are detailed below.

Of the 21 participating residents six were Irish, 13 were British, one was Indian and one Italian. The mean age was 83.2. The mean Mini Mental State Exam (MMSE) (Folstein, Folstein and McHugh 1975) score was 16.7 (see 3.4.3.4 for explanation). The mean length of stay in the care home of all participating residents was two years nine months. Of the 11 residents who participated in formal interviews, four were Irish and seven British, three were male and eight female. Ages ranged from 79 to 99 with a mean of 81.9. MMSE scores ranged from 8 to 30 with a mean of 22.9, i.e. more cognitively able than the residents overall. Formal interviewees had been resident in the home for between one month and 24 years with a mean of four years five months. Details of participating residents are presented in Table E in appendix I. This includes their degree of mobility as this affected their ability to enact decisions, biographical details including, whether born and brought up in the UK, marital status, existence of close family members, whether they had visitors, work before retirement and their living circumstances immediately before taking up residence in the Home.

Names have been changed to ensure confidentiality and for the same reason ranges were used for age and time of residents' stay in the care home. Similarly, to maintain confidentiality, nationality has been left out but whether a resident had English as their first language had relevance to both their experience in the home and the research process

so is included. The MMSE as recorded in the Home records is presented to assist the reader in understanding the diversity of cognitive ability that existed amongst participants. I did not look in the records or at the recorded MMSE scores until after my interviewing and observations were close to completion. I did not want these scores to influence me, in case this changed my behaviour towards residents.

It has also been reported where part of a resident's life was spent in institutional settings with group living. I considered that this could have an impact on how they would feel about the potential constraints of communal living in which they found themselves. Examples of institutional settings were, nurses in hospital accommodation, the armed services and nuns in convents. Health problems have not been specified to preserve anonymity.

Of the residents who were formally interviewed all except one, namely Iris, had capacity to consent to be interviewed. I found participants keen to help and happy to engage in conversation. None of the formally interviewed residents expressed any concern when asked about recording the interviews and more than one person admitted that they had forgotten the recorder was on. Iris gave assent to take part in the interview but I was uncertain that she could understand and remember the explanation of the study to enable her to give real consent. Consequently her sister in law, who was interviewed alongside her, gave her assent as a consultee, in keeping with the Mental Capacity Act (MCA) Code of Practice (2007).

Of the ten residents observed and engaged in informal conversations but not formally interviewed four people four had capacity and provided their consent. Their reasons for not wanting to take part in formal interviews varied. Vera just did not want "to be bothered" with the formal interview. Edna had expressive dysphasia, her limited speech made it impossible to interview her, however she understood the study and gave her consent to being observed and to my examining her records. Portia did not have English as her native language. She spoke very little English but understood it well and I obtained her consent while her son was present who could translate if required. Philippa was in a lot of pain and consequently declined the formal interview. The other six residents who were included in observation and engaged in informal conversation but were not formally interviewed lacked capacity to give consent and a consultee provided their assent.

I developed a good relationship with most of the residents over the time I was visiting the Home and collecting data. I was made to feel like a welcome guest in the Home's communal areas and in residents' own rooms. I reintroduced myself on each visit and again explained the purpose of my visits. The relationship and rapport established enabled me to collect data in an informal way which was open (i.e. not covert).

A number of residents were not included in the study, some because they could not consent due to cognitive impairment and for whom I did not meet any visitors who could act as consultees. Only two residents with capacity refused to take part. Both were British males. One told me that he was not interested, the other said after reading the information sheet that he could not see how it would help to change anything. I respected their refusals.

The conversational type varied considerably between residents formally interviewed. Some would talk at length in answer to questions, others gave one or two word answers and required considerable prompting. I tried to use open questions throughout the interviews. However, the difference between residents' style of response existed independently of the type of question. Those who responded with longer answers took more control of the direction of the interview. Inevitably, as the interview took the form of a conversation the content of the interviews varied as I allowed residents to talk about what was most important to them while trying to keep the interview centred on the research questions.

4.3.2 Participating relatives

Of the eight relatives who took part, seven were white British and one was Indian. Two relatives, Heather and Una, were interviewed alongside the resident. Information about the participating relatives is presented in tabula form (see Table F, appendix J).

Many of those interviewed had experienced some difficult times with their relative, through deterioration in their health, admission to long term care and coping with pragmatic issues such as their finances. During the interviews as well as informal conversations many wanted to talk of these times which often did not relate to decision making in the Home, consequently not addressing the research questions. For the sake of rapport and respect for the participants, leeway was given. Those relatives interviewed

were happy to be involved and all agreed to be recorded. Only one relative who was approached refused to take part, although others were not always interviewed due to difficulty arranging a convenient time.

The relatives and a friend who participated were generally the most frequent visitors. These were the people with whom I built a rapport and was able to interview on their normal visits. Although these almost certainly were not representative of all friends and relatives of residents in the Home, they were a good selection of those most aware of, and involved in, the care of residents.

4.3.3 Participating staff profile

Details of all the staff working in the Home at the time of the research is given in 4.2.2

Eleven members of staff participated, five were registered nurses and six were care workers. None of those who participated were born in the United Kingdom (UK). The average age was 42.3 (range 25-66), the mean length of employment in the Home was 5.8 years (6 months to 24 years). The mean number of years the registered nurses had been qualified was 20.6 (8-43) years. Three care workers were qualified nurses in countries other than the UK and, of the remaining care workers, two had NVQ3 (National Vocational Qualification) and the other NVQ2, working towards NVQ3. Two participants had English as their first language. More detailed information about individual participants has not been included as it would identify them and compromise their anonymity.

4.4 Analysis

The analysis process is discussed in chapter 3, 3.4.4. To ensure transparency of the process the Open Codes (see chapter 3, 3.4.4.2) applied in the analysis of participants' interviews and conversations, my observations and documentation, which were most germane to the research questions are presented in appendix K.

This chapter continues by reporting the findings in relation to the research question: What decisions are made in care homes?

4.5 Types of decisions

In the initial process of open coding, codes were identified relating to the decisions that were made. During the analysis process these were categorised under the three types; everyday decisions, infrequent decisions and advance decisions. They are illustrated in Table 1. This part of the analysis is largely descriptive rather than analytical but is an important part of the analysis nonetheless as they identify decisions from the perspective of participants. Dey (2007) suggested that categories in grounded theory must be analytical and conceptualising. He noted that according to Glaser and Strauss (1967), categories are indicators of the data rather than direct representation of them. The types of decisions are concrete and identifying them was included in my research questions. To be true to the grounded theory method, ‘Types of decisions’ should not come under categories as it is merely describing and organising the data. I have included the decisions that residents identified themselves as well as those I discovered through interviews, observations, informal conversations and in examination of documentation.

Table 1 Decision categories identified by residents and relatives

| Everyday decisions | Infrequent decisions | Advance decisions |
|------------------------|----------------------|---------------------------|
| Food | Medication | End of life decisions |
| Activities | Medical decisions | Funeral |
| Hygiene | Financial | Future hospital admission |
| Clothes | Hospital admission | Nominated decision maker* |
| Going out | Where to live | Power of attorney |
| Where to spend the day | | |
| Religious observance | | |
| Time to get up | | |
| Time to go to bed | | |

*A nominated decision maker, in this context, is the person who a resident has told staff is the person to contact in an emergency and who they would like to be involved in decision making for them should they lose capacity. This is an informal status with no legal recognition unlike a holder of a Power of Attorney (MCA 2005).

Decisions identified by residents then by relatives and staff are illustrated with examples from the raw data.

4.5.1 Residents' perspectives on types of decisions.

The everyday decision relates to personal care and many of the normal activities of daily living. These decisions listed in Table 1 were talked about by residents in interviews and informal conversations and were regularly observed as part of everyday life in the Home. Choice of food was a decision which had to be made daily and which was regularly mentioned, an example is given below.

From field notes 19.00 6/5/2010 Teresa approaches Queenie in the lounge with tomorrow's menu. She asks Queenie what she'd like. Queenie says "Well I'm blowed if I know what I'll fancy tomorrow!" Teresa offers her a choice of pork or fish. Queenie said "Pork I suppose it's not Friday is it?" Teresa says no and says I'll put you down for pork then and moves on to ask Ruth what she wants for lunch tomorrow.

Another example is given here of a resident choosing where to spend his day.

*Julia you're choosing to stay in your room,
Norman Yes,
Julia That's what you like to do?
Norman Oh yes, I'm asked if I want to go down after meals, down stairs, but I haven't been I prefer to come in my room, I've the radio to listen to,*

The infrequent decisions were those that were not made everyday, some were made only once. This encompassed decisions on where to live, finances, and health care. The importance that residents put upon them is not necessarily greater than for everyday decisions. There is an example below which illustrates this point.

*Julia But do you sometimes think the doctor makes decisions without consulting you?
Kieran I think so. But anyway that's not a serious matter. The serious matter is, when I call to go to the toilet nobody comes.*

An example of an infrequent decision, in this case about medication, is given below.

Nelly I've refused medicine before...I understand they're for pain killing.

Advance decisions included the establishment of a power of attorney, the nomination of a proxy decision maker and advance planning for when a resident was no longer able to decide for themselves. The advance planning usually related to major issues such as end of life care. These advance decisions were quantitatively different to contemporaneous decisions. They required planning and when the time came it was necessary to make a

series of new decisions on whether, the resident has lost capacity for the given decision. the situation is what was anticipated by the resident, the decision should be carried out regardless of the wishes of relatives and how the decision sits with the team's view of what is in the resident's best interests. Where a power of attorney was in place, once it was established that the resident lacked capacity to make a decision, there was little controversy as the decision maker had legal power as long as they were acting in the resident's best interests. Nomination of a proxy decision maker gave that person a moral right to be involved in the decision making, but no legal right to decide. Whereas everyday decisions and the infrequent decisions varied only on a scale, the advance decisions differed in kind. Consequently, advance decisions have been discussed separately. Examples of advance decisions are given below.

Nelly ...my son has power of attorney, they do all the financial things, anything to do with my home,

Katherine we've got an insurance policy for £1000 each to cover our funeral costs.

4.5.2 Relatives perspectives on types of decisions

Data from the relatives predominately identified decisions similar to those discovered through interviews and conversations with residents and my own observations. However, the focus of which decisions were their domain was unique to relatives and friends. This focus is discussed throughout the findings chapters. They talked most frequently about infrequent decisions, namely, residents' admission to the Home, medical treatment and financial matters.

4.5.3 Staff's perspective on types of decisions

All staff identified decisions that were made in the Home even if they were not involved in making them. Interviews and conversations with staff did reveal other decisions to those identified by residents and relatives. These have been categorised in the same way as the decisions identified by residents and relatives (see Table 2). Different categories of staff were involved in different types of decisions. The everyday decisions were more likely to be faced by care workers. although they did not always recognise the decisions they were making. The infrequent decisions, often related to a resident's illness and possible hospital admission, were normally the domain of registered nurses. Care planning was also the responsibility of registered nurses with care workers following what was in the plan.

Nevertheless, care workers did have to decide when to tell a registered nurse if they considered elements of the care plan inappropriate. Risk assessment has been included in both the everyday and the infrequent categories. Risk assessment is interpreted here as the sort of informal assessment a care worker makes every day during delivery of care, e.g. transferring a resident from bed to chair, but also refers to the formal, written risk assessment a registered nurse may perform regarding the risk of a resident falling if they go out alone.

Table 2 Additional decisions identified by staff

| Everyday decisions | Infrequent decisions | Advance decisions |
|----------------------------------------------------|----------------------|-------------------|
| Asking for help | Consulting others | Care planning |
| Deferring decisions to another | | |
| Risk assessment | | |
| Passing on information to other staff or relatives | | |

Below is an example in which a member of staff passed on information to a relative.

***Janine (registered nurse)** Then we inform already the relatives that he's deteriorating...So, we are giving our idea that just in case, you know, that condition is becoming worse, you know we are sending in the hospital.*

This is an example in which staff defer decisions to another.

***Hope (care worker)** Yes, I still say the decision is go to the manager and the RGN in charge it's not for the carer to decide what to do.*

Here is an example in which staff ask for help,

***From field notes** Pamela told me that she tried to wash Sara this morning but that she was in a "bad mood". Pamela showed me a red mark on her arm where Sara had grabbed her. She told me that was what the noise was, I could hear Sara shouting. Pamela said that she had tried a couple of times but when Sara had grabbed her arm she told the nurse in charge and she had gone in with another care worker as Sara needed to be changed.*

There follows an example in which staff consult others to aid decision making. Janine was talking about a newly admitted resident who had dementia and appeared to be unable to walk.

***Janine (registered nurse)** we are trying to leave her to the physiotherapy, occupational therapy or we will ask as well, you know, the community nurse to come and do the assessment.*

Staff involve relatives in care planning in this example.

***Marga (registered nurse)** The relatives, that obviously because we normally involve them when we do the care planning*

Examples of informal and formal risk assessment are given below.

***From field notes** Pam was sitting in the lounge and looking a bit agitated, she got out of her chair. Chrissy was passing the door and saw her and came in. She said to Pam that she'd been a bit unsteady lately and perhaps she would like to take Chrissy's arm. I saw Chrissy whisper in Pam's ear and saw them slowly walking to the toilet together.*

***From Home documentation** A Waterlow pressure sore risk assessment tool was completed for all residents. This was followed by a document proposing given actions depending on the score, e.g. pressure relieving mattress.*

The first example above indicates Chrissy identifying a potential risk of Pam falling and her actions to reduce this risk. The second is a formal risk assessment conducted on all residents on admission and at three monthly intervals thereafter.

4.6 Discussion and conclusion

This is the first of three findings chapters. It has introduced the participants who took part in the study. It has discussed and given illustrative examples of the three categories of decisions that were identified, the everyday, the more infrequent and advance decisions. From the residents' perspective, there was more emphasis on everyday issues. They were most concerned with and involved in issues relating to their everyday care, where they spent their day, choosing food and their daily activities. Relatives showed concern about the way care was delivered and residents' everyday life but in interviews, they concentrated more on the infrequent decisions, specifically about where to live, finances, and health care. Advance decisions were discussed with each group of participants during interviews and information from the notes further illuminated the issue. This category of decision is discussed in the following two chapters. These two chapters present the findings, chapter 5 on the resident as decision maker and chapter 6 on others deciding for resident.

Chapter 5

Resident as decision maker

5.1 Introduction

This chapter explores the findings relating to the first of two central phenomena identified, “resident as decision maker”. I have followed the grounded theory process suggested by Strauss and Corbin (1998) in which they offer the paradigm model of central phenomenon, built from the axial coding. The analysis process is detailed in chapter 3. 3.4.4.

The chapter begins by exploring the evidence on perspectives of what is a decision maker, before considering the causes, context, intervening factors, strategies and consequences that underpin the central phenomenon of resident as decision maker. This chapter addresses the research questions; Who makes the decisions and with what authority and/or responsibility? What are the barriers and facilitators for residents to making their own decisions and what factors influence relatives’ involvement?

The chapter concludes by presenting this evidence in a figure of the model suggested by Strauss and Corbin (1998) (5.6, Figure 1).

Open codes (see chapter 3, 3.4.4.2) are presented in appendix K.

5.2 Views on what constitutes a decision maker

The understanding of the term ‘decision’ varied amongst participants.

Some residents suggested that they made few or even no decisions at all and this is demonstrated in these examples.

Julia...what decisions do you have to make every day for yourself?
Victor I don't have to make really any. It's all done for me.

Julia...what sort of decisions do you have to make when you're living here?
Queenie When I'm here?
Julia Yes what sort of decisions do you have to make?
Queenie Oh gawd, I don't know I don't make any

This related to their perception that the sorts of decisions they, on questioning, agreed they were making were mundane, about their everyday life. Decisions, as they reported them, were about, ‘important’ matters such as health, finances or planning for end of life. All decisions are included here, although perhaps the word choice rather than decision might be better understood as at times the interviews showed that participants recognised the term choice more readily than decision as what they made in their everyday lives. Sometimes choice was easier to apply to residents with cognitive impairment as decision is inclined to invoke the perception of a need for a higher level of capacity and autonomy. The difference between choice and decision has been discussed in chapter 1, 1.2.

Some residents considered the decisions they made about their lives to be of no significance as Nora says here.

***Julia**...what sort of decisions do you have to make or are made here?*

***Nora** Ey, I don't make any decisions darling, I've never ever had to take part in anything like that. I've never had to make a decision, except something that was immaterial, something not very important.*

Conversely, others considered themselves able to decide everything for themselves as in this example.

***Julia**...are there any decisions you feel you can't make, don't make, that someone makes for you?*

***Laura** I nearly do all of them on my own.*

My observations showed that there was little difference between the type and number of decisions made by those who reported they made no decisions and those who said they made all their decisions. It appeared to be a difference in perception. An explanation for this can be found in the background of the residents. Laura had lived her life in an institutional setting and consequently she had never had the opportunity to make more decisions. Someone like Queenie had run her own house, had a responsible job and had been strongly independent in the past. Relatively, Queenie's decision making had been much reduced. People's perceptions came from a large number of sources but the change from past experience to the present appeared to rank highly. This history fed into both their beliefs and expectations.

Relatives also often considered that residents made few if any decisions, similarly seeing the everyday decisions as too inconsequential to be considered. Further, it was particularly noticeable where relatives and friends knew the resident as previously being a big decision maker.

Patricia did not consider Queenie to be a decision maker as a resident in the home as is demonstrated in this quote.

***Patricia** Erm, well she doesn't have to make decisions really does she? I mean what decisions would she have to make now?*

Queenie's friend speculated on why she might choose not to make decisions on her own behalf, considering she might feel secure and thus be happy to delegate the responsibility as the example below suggests.

***Patricia** Because erm I mean she might, because she feels secure here she might think well let them take the flak, or take the strain,*

She noted that Queenie used to like to have control when she was at home so this passivity was a big change in her. Queenie expressed her belief that her actions would do little to change her situation rather than saying she was content for others to decide (see 5.4.1 below).

It was observed by more than one relative that residents, those with mild or moderate dementia included, could make their voices heard to staff and would be happy to do so as shown in this example.

***Jane** She's not backward in saying what she thinks about things.*

Relatives generally believed that residents made the decisions they were able to themselves, although some relatives thought that staff were not always good at reading non verbal signals.

5.3 When a resident decides

All residents discussed everyday decisions relating to activities of daily living that they made, e.g. what to wear and where to spend their day. The example below is a case in point.

Julia *So what about getting up, if you want to you can ask them to get you up, otherwise you choose to stay in bed?*

Nelly *I can get up if I want to. They'll ask me if I want to get up when they're washing me in the morning, they'll ask me if I want to get up and I'll say yes or no depending how I feel.*

Julia *And they'll do as you ask?*

Nelly *Yes, they will.*

All the residents, even those who perceived that they made few if any decisions, identified infrequent decisions that they took, e.g. who would act as a nominated decision maker should they be unable to decide for themselves and all had at least some involvement in their financial affairs. Examples of each of these are given below.

Julia *If you weren't able to make decisions who would decide for you.*

Victor *Carol would.*

Julia *You've got your own bank account which you manage?*

Geraldine *Oh yes.*

Julia *Nobody else is involved,*

Geraldine *Oh no. I get a little from the social services every week, I get a small amount which is very helpful.*

Julia *Yes, but it's all under your control the money, that's what I meant,*

Geraldine *That's right. Yes,*

Jane also commented on Ruth's independence enabling her to make her own decisions about when to wash and dress and what to wear.

Jane *I think she's independent. She doesn't have anyone to wash her and dress her, carers, so she makes her own decisions about...*

As she was physically independent it was easier for her to enact decisions around everyday issues. Ruth communicated well which was also an advantage for her in asking for what she needed. Those less independent and able to communicate their decisions needed more assistance from staff.

Staff generally suggested that residents were the ones who decided, at least about the everyday issues affecting their lives. There was recognition that residents could demonstrate preferences about their everyday care either verbally or nonverbally even if they had dementia.

Chrissy (registered nurse) ...if somebody's not able to communicate verbally, definitely there will be signs of, you know the agreement or disagreement by physical language so you need to take into consideration everything and I like to say that the decisions are made by the residents themselves and we try to keep that on.

As Chrissy suggested in this example, in most cases staff indicated that they would have prioritised residents' choices over that of their relatives at least in relation to everyday decisions.

Chrissy (registered nurse) I mean I will go, I will stick with the patient's choice because at the end of the day we are, they are our, we are working with them than the patient's relatives choice. You know, because they come second but priority come to my patient.

This was not always the case, particularly for infrequent decisions (see chapter 6, 6.2.3). There is more information on how staff affected residents' ability to make decisions in the following sections.

5.4 Facilitators and barriers to residents deciding

5.4.1 Residents' characteristics and strategies

A significant number of both facilitators and barriers to residents making their own decisions related to characteristics and behaviours of the residents themselves. The open codes are presented in appendix K.

Residents' desire to take part in decisions and the perception of how much they were able to, and in reality did participate, varied considerably between individuals. Although some residents did appear to be content to allow others to take decisions for them, others expressed the belief that they could not control their lives to the degree they wanted. Residents demonstrated a range of behaviour in relation to decision making, from passive acceptance to active assertiveness.

Some were quite determined to make decisions about how and when to receive care and were willing to assert themselves to achieve this as Katherine demonstrates in this example.

Katherine *All that is me organising. I have to bug them, to say you know it's time I had my pills, why haven't I had them yet, except for, then I have to phone about ten past nine and say why haven't I had my milk and sandwiches yet, and err then I have to say why haven't you put my mask on, and then they say well it wasn't time and it's after the time, I really have to be a bit of a bitch.*

Julia *Yes, but you get things done.*

Katherine *Oh yes, it can work.*

Another resident said that if she was dissatisfied with her care and the way it was delivered she would tell staff. In this example she reported that it was important to demonstrate that she was not stupid and in that way ensure that staff listened to her and delivered care in the way she wanted, giving her some control over a situation where she was physically dependent.

Nora *...you've got to let them see you've got a bit of common sense, and that you understand what they're doing and that you're not an idiot. You know you can, you know what's happening and that, you've got to let them know that.*

Katherine was willing and able to take control over some everyday issues such as what to wear, as demonstrated in this quote.

Katherine *I tell them what I want to wear and if it's really important I lay the things out.*

Queenie was clear that she considered it appropriate to ask for the food she wanted. She stated that if she was unhappy with the food she was given she would ask for an alternative and that staff would find her something else.

Queenie *Well I don't see why I shouldn't ask for different things.*

No other residents said that they would do this, apparently not considering that choosing something not on the menu was an option. My observations showed that when residents said they did not want or like the food they were frequently given alternatives. Although I heard residents complain that they had not been given what they had asked for, I did not hear anyone request specific alternatives. Complaints came mostly from residents with memory problems, emphasising the difficulty of asking people to decide the day before.

Many residents were passive and did not attempt to take control over decisions. Queenie's comments below contrast with the previously quoted more assertive remarks relating to food choice.

Julia And if there is a care plan written for you, so that's about how you should be cared for, would you be keen to see it?

Queenie No not necessarily.

Julia You're not bothered.

Queenie No. It'll go on anyway.

Julia So when you were younger you would have wanted to make all your own decisions.

Queenie Oh yes!

Julia But you're not bothered now?

Queenie No I'm not bothered now, well you can't be in here can you?

This is markedly different to the independent person she had been before. As has been noted already, her friend Patricia told me that she had been strongly independent and made considerable effort to maintain control when she was at home, even when she had carers and was dependent on them for many of her needs. She was also voicing here her view that there was little she could do to change her circumstances, apparently considering herself to be in a powerless position. This could explain the difference in her request for different food which experience showed would have an effect, while believing that care plans changed nothing.

Another reason vocalised for a resident to allow others to decide was a lack of faith in their own ability, as Victor demonstrates here.

Julia ...do you choose what to wear?

Victor No Carol buys all of my clothes.

Julia And you're happy with that, you're not bothered that you don't choose them yourself?

Victor Oh no, no, no. I'd buy the wrong thing really.

When asked about the choice of food Victor thought the choice could have been better but expressed appreciation that there was always enough to eat and he could always ask for more.

Victor We've got plenty to eat, we're not, we're never hungry, no we're never hungry and the beauty about this place is if you get down a meal and you haven't enough of it, you ask the carer to ask the chef to send you down more, and he will.
Julia Good, that's really important isn't it?
Victor They're very good, you never go hungry here.

Julia What about your meals?

Victor Well I have my meal, I'm lucky I'm allowed to have my meal in my room,

In these examples Victor indicated low expectations and gratitude for things to which he was entitled.

Karen also had quite low expectations in relation to the food. She had asked for food which differed slightly from the menu and was generally satisfied with what she was given. However, she expected that there would be limitations to the food staff could provide due to cost and the need to cook for a large number of people, preventing the food from being ideal. She said;

Karen Oh well that side is such I don't know how they, what's the word, economise and how they have a balanced diet for the home, it's of course large quantity cooking for that part is huge, but you can't expect it to be homely,

As this quote demonstrates, Geraldine's desire for independence was found in her reluctance to go to the shops.

Julia You don't feel the desire to go out to the shops,

Geraldine No

Julia You don't want to do that,

Geraldine I'd have to go, I'd have to ask them to bring me, it's the dependence on someone which is very alien for me.

Julia You don't like the dependence do you?

Geraldine No, not at all, I'm terrified to lose my independence.

A member of staff went out to buy what she wanted, so her concerns related to her physical dependence.

Some residents were unable to do as they wished due to being physically unable. Nelly said she would have liked to cook her own dinner.

Julia But you don't feel there's enough to choose from there's not necessarily something you like.

Nelly Not something I would have, no, I would want to cook for myself.

Unfortunately due to Nelly's health she would have been unable to cook and no amount of facilitation could change the fact that Nelly was severely disabled due to her stroke and was unable to cook.

Laura was always keen to help around the home. She laid the table for lunch each day. She said that she used to help take the people in wheel chairs to the dining room but was disappointed she could not do this anymore as the chairs were too heavy for her. As residents' physical ability diminished, inevitably there was disappointment that they were unable to do what they had done before. Some residents did have unrealistic expectations of what they could physically do but staff did not always take opportunities to assist residents in finding what abilities remained and help them make the best use of these abilities.

Relatives often commented on the significant changes in the residents, especially amongst relatives of residents who had a greater degree of cognitive impairment. This is evident in Christina's comments.

***Julia** Do you think he makes any decisions for himself now really?*

***Christina** Not at the moment I don't think, no. Not, no I haven't heard him make any decisions of any description, I said to him once or twice, you should do this or you should do that, but he doesn't seem to take any notice,*

During the interview she was inconsistent about her view of David's cognitive state and his ability to make decisions, moving between the expectation that he would speak out as the strong willed, independent husband who used to make all the decisions for both of them and a changed "pathetic" man.

***Christina** David has made all the decisions, more than I thought, and my sister said you've just been spoiled all your life...I mean to me, he's just not the same man...no I haven't heard him make any decisions of any description...I find him pathetic to what he was.*

Here Christina noted the change in David, from the strong decisive husband, to a person who was unable to decide whether to get out of bed. David was unable to make many decisions although he did sometimes express preferences nonverbally. This example of the change in the resident was the most extreme but the theme was evident in most interviews.

Molly talked about how her mother wouldn't let anyone cut her broken fingernails. She talked of the change telling me that Jeanna had been concerned about being well groomed in the past. Molly also pointed out that her mother no longer made decisions but Molly was unsure whether this was because she was cognitively unable or just unwilling. This contrasted dramatically with the strong, determined lady who knew what she wanted that Molly told me she had been prior to a hospital admission that led to her entering the Home.

These changes appeared to make it difficult for relatives to perceive what residents' remaining abilities were, to assist staff to maximise their opportunities to be actively involved in life in the Home. Although the relatives recognised nonverbal signals they did not necessarily equate this with decision making.

Residents' assertiveness, expectations and physical ability strongly affected their involvement in decision making and whether they could enact the decisions they made. As has been reported, attitudes also affected how residents perceived their opportunity to make decisions. Dependency and the need for care puts residents in the power of the staff who provide that care. Although those with the most severe physical disabilities were potentially the most powerless, higher expectations and more assertiveness mitigated this powerlessness.

5.4.2 Routines, systems and policies

Residents' choices and decisions were restricted by a number of practices which appeared to take place without question. Routines, systems and policies were an accepted part of daily life in the Home which residents complied with and did not mention in interviews or informal conversations. Some decisions were limited purely by what was available and the choices offered. This included activities and what to eat. Some routine practices, systems and policies in the Home affected residents' options and consequently their decisions.

The choice of meals was something residents, relatives and staff considered most residents were able to make. A choice of food for their main meal, served at lunchtime, was offered to residents, they were asked to choose the evening before. Choice was between two or three dishes. As has been discussed already staff confirmed that if a resident did not want what was on the menu an alternative would be found as in this example.

Chrissy (registered nurse) Their choice of meals, they have a choice of course and if they want to stick to that that's fine, if they don't we'll try to give alternative choices.

Staff often facilitated choice by being flexible and providing residents with food they found acceptable at the time. They were identifying and responding to individual preferences. However, observation showed that few people asked for anything specific but it was more common for residents to say that they did not like what they had been given.

From field notes Feb 17th 18.00 (approx) Most of the residents were sitting at their usual tables waiting for their food. Pilchards on toast was brought to a number of residents. Iris pushed her plate aside immediately and said "I don't want that, take it away". Anna quickly took it away, saying OK, she'd find her something else. Iris did not seem to mind waiting while most other people were eating. Anna returned a few minutes later with some beans on toast which Iris ate with enthusiasm.

This example shows that Iris was given what she considered a suitable alternative but was not offered a choice between alternatives.

Some residents were generally dissatisfied with the food, what was provided did not suit everyone. In this example Nelly thought that not only was the choice limited but also that the meals were inappropriate.

Nelly they come round with a piece of paper about 6 o'clock in the evening and ask you what you want for dinner tomorrow as though you know what you want for dinner tomorrow, they say there's, just for example there's sausage and chips you know, sausage and chips or macaroni cheese, you've got that choice, you haven't got really much of a choice, you can only have what they've got on the menu you know what I mean? That was what I was arguing about today, that I haven't got a choice, they said you did have a choice you had a choice of having erm omelette or something else, I said that's not what I got, I said I got the omelette, I didn't get the rest of it, I said I didn't get the bacon that it said on the menu we were going to have. So I didn't particularly want the bacon anyway, I don't like the meals here very much, not a very good chef I don't think, I said to the manager you got enough money, to do a proper meal, it's nothing to do with money she said I said it's got to be you can't afford to make a proper meal, just use the scrambled egg, I've never heard of it I'll be quite honest with you, you might give it to a child, I've never heard of it being given as a meal on a Monday, scrambled egg and 3 parsnips and 3 sprouts, it doesn't seem right to me all these elderly people they're quite old they need proper nourishment don't they?

This opinion was not universal with some residents saying they were satisfied with the food and the choices. The need to choose in advance was understandable to avoid waste but was criticised by a number of people. Some residents with short term memory problems told me they were not given a choice of food, whereas I had seen them asked the previous evening. For these individuals the time between being asked and receiving the food was too long for them to remember, thus they often forgot what they had ordered or even that they had been asked at all. Some residents simply wanted to change their mind. I saw in periods of observation that wherever possible staff accommodated this and provided alternatives.

In this example Victor found the choice somewhat limited.

***Victor** Oh, well you can't very well choose with the chef, he puts down on a piece of paper what's going to be ready what you're going to have the next day, like what meat and that you're going to have the next day and you tell them if it's OK. But they'll have that.*

***Julia** So is there a choice of two or three things that you get choose from?*

***Victor** About two, only about two things you can choose from.*

***Julia** Is it usually OK, do you feel you have enough choice?*

***Victor** Well it would be better I suppose if there was three you know what I mean? They may not do, they may, I mean, they may when they're doing the cooking they may only do two things.*

There was evidence of some flexibility around menus. Two Indian ladies moved into the home at the latter part of my data collection period and food appropriate to their cultural background was served and when I asked if they enjoyed their food they both spoke enthusiastically about it.

The main meal was routinely served at one o'clock. This routine was not questioned by any participants in interview or informal conversation. My observation showed that residents got up at different times, mostly at their own choosing, and breakfast was a flexible meal. This meant that some residents were not finishing their breakfast until after ten, so it was easy to understand that they might not be hungry at lunchtime. The chef only worked in the morning so there was little flexibility. A kitchen assistant prepared the evening meal which consisted of some hot snacks and sandwiches. It was possible to reheat a meal from time to time but with food hygiene issues and the practicalities this could not be done for more than one or two residents nor could it be done on a regular basis.

Another area where residents' decisions were restricted by the choice offered was in the organised activities. The Home had an activities coordinator and a number of activities took place, these included singing by residents or by others, exercises, cards, reading, usually of biblical stories, etc..

The activities coordinator told me he talked to all residents soon after admission whenever possible, about their interests, hobbies and types of activities that may interest them and he documented this. From this documentation I saw some individuality was evident and the activities coordinator told me these were completed with the residents. Nonetheless, there were a lot of interests that were repeated. Many of these were activities that residents in a care home are likely to be able to do e.g. watching television, listening to music and reading books and what group activities can be offered in the home, such as those listed above. Some other activities which did not fit these categories were listed such as nature and scenery and cooking. Few residents went outside the Home at all, and as far as I know no one went outside the city, so the opportunity to see nature and scenery was limited. In conversations with residents about trips out, some residents did say they would like to go on outings but if more specific plans were mooted reluctance set in. There was a concentration on the activities that were possible and easy to organise and this was largely reflected in the activities coordinator's documentation.

Some residents enjoyed the organised activities as in this example.

Julia ...you go in for a lot of the activities, I've seen you with the sing songs and playing cards and things,

Nora Yes darling,

Julia You enjoy all that don't you?

Nora I enjoy it so I do,

Others were clearly not keen as illustrated in this example.

Julia ...the sing songs and so on, you're not really interested?

Queenie Oh Lord no! That's the last thing I'd be interested in.

Julia Yeh, you just stay out of the way if anything like that's going on.

Queenie Umm,

Julia what about the religious activities, are you a Catholic?

Queenie No

Julia So you don't have anything to do with the religious activities in the home.

Queenie Not really no.

Queenie showed a lack of interest in the types of activities laid on. It was inevitable that not all residents would be interested in the group activities. As there was only one activities coordinator he had to cater for as many people as he could, consequently all activities took place in the lounge or garden and he did not have time to go to the rooms of residents who preferred not to come to the lounge. If a resident was not keen on the activities in the lounge they could go to their room. For those who were not mobile this required the resident to enlist help to move them and for them to be taken and this often resulted in a delay.

Here a resident suggested that her reason for not joining activities was the characteristics of other residents.

***Julia** And what about the activities that they have down stairs, I know you're reluctant to go downstairs, do you feel you're missing out or are you not bothered?*

***Geraldine** No not at all.*

***Julia** You don't want to play bingo or join in a singsong.*

***Geraldine** No not at all. No I don't feel I miss out on anything. I wouldn't want to, I wouldn't, when I first came here I always went to bingo, it was lively. But there's no life. If I went down now there's no life.*

***Julia** And that's because of the nature of the residents now they're older and less well,*

***Geraldine** Exactly and there's nobody, there's nobody can help that.*

She had previously commented that most residents had dementia and that it was difficult to converse with anyone. She noted that residents had gradually become more dependent and less able over the years she has been a resident. This left her feeling isolated. The choice to stay alone in her room rather than joining other residents in the lounge was her own, but as she felt that she was unable to converse with the residents she believed that going to the lounge would do nothing to alleviate her isolation. A single activities coordinator meant that Geraldine did not receive individual activities although she did maintain an interest in current affairs, read a daily paper and enjoyed watching television.

The diversity in the abilities of residents limited the activities offered to both the most and the least able. Activities were offered in which the largest number of residents could participate. To challenge the abilities of the most able and to creatively find the remaining capabilities of the least able was beyond the scope of a single coordinator.

In the example below the resident made a decision regarding her money but was unable to carry it out until the appropriate member of staff was available to assist her.

***Karen** I have about £70 in the office and it's so difficult to get it out when you want something, you have to wait until sister so and so is in the err, like in the safe. You have to ask sister there, you have to ask sister to get the key and she will open, that's the sort of system, they have to have security,*

She demonstrated an understanding of the problem of having to balance the need to keep her money secure and her ability to access it when she wanted. However, there was an element of irritation evident as the system interfered with Karen's choice. Residents with capacity did sometimes take charge of their own money, but this was not without its problems as is demonstrated in this example.

***From field notes** When I came in this morning Abeo told me that Geraldine had lost £60 that had been in her room. She said that everyone was upset and {the manager} was saying they would have to call the police if it wasn't found.*

I also witnessed a similar incident where Katherine reported her handbag, containing some cash, missing. The money was found in both these instances but not before considerable distress was caused to the residents who had lost the money, staff and other residents. Consequently, only those residents who were insistent on keeping their cash with them did so.

As has been recorded above, residents were generally able to choose what to wear. However, this choice was restricted by what residents were able to buy after admission to the care home. Karen told me that she was wearing clothes she had bought some years ago as they had been good quality and looked after. Victor was happy with his niece Carol shopping for him as he considered her more able to buy the right thing than him. However, a number of people bought from people who came into the care home to sell clothes as the examples below show.

***Laura** Well there's, they have the clothes people come. The Indian clothes people. Her name's Diana. And I can get clothes from her.*

***Julia** And what about buying clothes and things?*

***Geraldine** The erm, what do you call, how do you use it, they have people come, quite regularly,*

***Julia** Yes, and are you happy with what you can get from them?*

***Geraldine** Oh yes.*

These residents were satisfied with this arrangement but this was a situation where residents are kept separate from the community. Further, this was seen in that no one went out to the hairdresser but by arrangement of the management a hairdresser came into the Home. With the exception of Katherine and Kitty, none of the residents went to the shops although staff willingly went out and shopped for residents at their request. Also, there was a chapel in the home where Mass was celebrated each Sunday, so although the church was next door, the residents no longer went to church with other members of the local community. However, none of the residents reported this as a problem.

The Home's policies, procedures and routines had an impact on the opportunity for residents to make choices. Choices were sometimes limited, at times to benefit as many residents as possible, with limited resources not allowing benefit for all. Some practice in the Home led to residents being isolated from the local community. It is notable that other than in choice of food and activities these issues were not raised by any participants but were accepted as the norm.

5.4.3 Relatives impact on residents' ability to decide

Relatives' level of involvement in the care and decision making and whether a resident had regular visitors affected residents' ability to make decisions for themselves.

Residents frequently said that they were assisted with decision making by relatives, helped in executing decisions or in some cases they had delegated decisions to relatives. This was a collaborative process. Not all residents were unhappy with others deciding on their behalf (staff or doctors) but in those instances there was not the consistent theme of collaboration to which residents referred when speaking of their relatives. Relatives did make decisions on behalf of residents and this is discussed in the following chapter of others deciding. However, the residents interviewed were able to make many decisions themselves and they told me that relatives did not decide for them except at their request. The quotes below are two of many examples of residents making joint decisions with their relatives.

Victor I'd ask her advice yes.

Julia You ask her advice to help you decide

Victor Yes I do that now. Yeh.

Julia *So then it becomes a bit of a joint decision.*

Victor *A joint decision yes.*

Hilary *I'm always glad to have Heather involved in decisions,*

Depending on the resident's level of physical dependence, after making a decision they would often need some degree of support if they were to enact that decision. Residents reported that support was offered by both relatives and staff. Staff's assistance was most evident in everyday decisions and in their delivery of care, while relatives were more likely to help with decisions about infrequent decisions, for example, their finances or where they lived.

In issues relating to financial affairs it was common for residents who were able to and wanted to make decisions to still need the assistance of another person, usually a relative, to execute those decisions. As Nelly said, the family first informed her of what they considered needed to be done, they then sought her agreement and only then did they carry out the action. Consequently, in the case below Nelly needed assistance to decide first by being given appropriate information and then further support for that decision to be enacted.

Nelly *They {the family} do all the financial things, anything to do with my home...they see to it all for me and they tell me all about it and I agree with it and tell them what they can do you know like moving from here they have to have my permission.*

Another resident was happy to pass the financial decision making onto a relative.

Victor *I have to pay, the simple reason that I've got a house. And Carol {his niece} looks after that and she has it let. I suppose she uses some of the money for, to pay for me here in the home.*

Julia *Yes. So your financial affairs, so is Carol dealing with those?*

Victor *She deals with them.*

Julia *So she does have access to your accounts,*

Victor *Oh God yeh, I'm entirely happy with it.*

Victor was happy to abdicate responsibility where he could. He had made a decision to allow another person to decide on his behalf. He had talked about his view of his own short-comings and that he considered Carol to be more intelligent and more able to decide than himself.

This dependence on relatives to give support was a common theme. Nelly sought the support of family to speak up for her about issues that were important to her. She was being helped to execute her wishes through the assistance of her daughter. As the example given here shows, Nelly was conscious that without her daughter's help her wishes may not have been considered as her executorial capacity was limited.

Nelly ...she has been very good has Una. She does see to, she has a go at them about me you know, I don't know what I would have done without her,

Relatives were supporting residents in decision making by giving them information, offering advice when it was solicited and assisting with the practicalities of carrying out decisions which the residents lacked the physical capacity to enact. In situations where relatives did decide for residents, this was at their expressed request.

5.4.3.1 Unwise decisions

There were examples where relatives were concerned that residents were making unwise decisions and these were not challenged by staff. In this instance the relative was questioning whether her uncle should be allowed to make, what she considered to be unwise decisions about his everyday life.

Carol I think Victor is asked whether he wants to have a shower today erm my issue is that he will often say no because he doesn't want to do it, and I don't think that's sensible and also he will when he's feeling low he will decide to stay in bed, and I've asked them not to allow him to do that because he does feel better when he's been out in the garden and he's been, you know even if it's only interacting with somebody just going, just waving at him as he goes past, so I think there are sometimes when they try to allow some decision making but perhaps not appropriately and I have actually said to them look I know how difficult this is I know there are times when he will say I don't want a shower but actually he needs a shower. He would comply if he was told actually your back won't get better unless you have a shower today Victor then he would have a shower.

Although this was about showering and where to spend the day Carol was seeing bigger implications. He had a pressure ulcer which she had been told would heal better if he showered regularly. As Carol said, Victor would have taken little persuasion from staff to have a shower if they suggested it was necessary. In regard to his staying in bed, Victor suffered from depression and Carol said that she was aware that staying in his room all day would lower his mood. Staff were opting for the negative view of autonomy in leaving Victor alone rather than going for a more creative way of supporting him to make the best decisions for himself. It was quicker and easier to leave him in bed than to get him

up and assist him to shower. This may have led staff to take the easy option. Carol was trusted by Victor and her involvement may have led to her encouraging Victor to change his decision to what she considered would benefit him more.

5.4.4 Staff impact on residents' decision making

It was observed that staff facilitated and impeded residents' ability to make decisions on their own behalf and have these decisions enacted. Staff affected residents' ability to decide, in whether they had time, were willing to assist them in a flexible manner and in their level of communication skills. Open codes are presented in the Table H in appendix K.

5.4.4.1 Staff strategies: risk, rules and fear of harm

Residents who were physically dependent and had cognitive impairments were particularly dependent on others, often staff, to assist them in making and enacting their decisions. The willingness of staff to allow residents to take risks of their own choosing was also relevant.

Staff had a number of strategies that they employed to facilitate the everyday choices of residents. Where to spend the day, when to shower, what time to get up or go to bed were easy decisions to make but were beyond the physical abilities of many residents to enact without assistance. Staff sometimes facilitated choices, for example, by showing residents a choice of drinks so residents whose verbal communication was impaired or had difficulty with abstract decisions could still express their choice. The same applied with staff showing residents' a choice of clothing as in the example given here.

Anna (care worker) Well most of the time before you dress up someone of course you ask them what they want to wear. If they say they can't reach the wardrobe you can try to take out a couple of items to show them they tell you might come to a decision and say because if like someone can't get to their wardrobe of course they won't even know sometimes what is in their wardrobe, how it looks like but if you keep bringing out to them then it will jog their memory and "Oh OK I can wear that or that"

Victor decided that he would like to spend time in the garden but as he was wheel chair bound he could only reach the garden with the help of staff. So although he could make the decision he could not execute it unaided. The example below illustrates his need for assistance.

Julia ...you spend a lot of time in the garden don't you, you like it out here?

Victor I like it out in the garden.

Julia Yes and they bring you out in the morning and you go in for meals?

Victor I go in for meals and then they bring me in the evening,

This need for assistance applied to many residents in relation to the everyday decisions that affected their lives.

I asked Chrissy about Laura (a resident with capacity who had previously had a fall), about her going outside the home as she had before she fell.

Chrissy (registered nurse) ...when she had the first fall it was difficult to make that decision whether we should send her off or not but then again, you know, your clinical experience and judgement you make, you oversee it and you monitor the patient if she's safe to go then why not? You know, if you are in the home you do the same thing, in your own home, you do it. So at least now we know that she is out and if she's delayed you know that there must be something holding her up and you can look for it. Now I agree that she could go, I mean if somebody wants to go, yeah I would.

Julia Yes, even if you think they are at risk and if you think they're not very safe but they really want to go are they able to decide?

Chrissy At minimal risk, if it is a high risk then I will escort. But, you know, I will try to accommodate their needs as well as prioritise our work because if she wants to go now, now, where I have a lot of things going on I will say "you know probably Laura, we could do this in the afternoon because then I will be a bit free so I can send somebody with you", instead of arguing with them.

This approach involved her assessment of the situation and the risk involved. She also noted that if Laura had been in her own home she would have been free to choose to take the risk. She would still have been reluctant to let Laura go if she felt she was at high risk but talked of negotiating with her about being escorted and avoiding conflict. This was in strong contrast to Hope (care worker) who was catastrophising the risk (see quote below). Hope suggested that she would be blamed for any accident that she might have been able to prevent by restricting Laura's movements.

Hope She, no if she wants to go on her own, she can't go on her own because she can hurt herself, she can fall, she can get accident on the road, we can't allow her to go on her own.

Julia So because of the risk you would stop her, you would actually stop her.

Hope We are stopping her, we are preventing her not to have an accident. Yes, the risk, because sometimes when she go out and she fall. And the police will come here said somebody fall on the way you know.

A number of techniques were used by staff to provide care to reluctant residents. Care workers often said that they would go to a registered nurse or the manager with this type of problem. Many of the care workers, as in the example of Pamela below, said that you could not force a resident to have care under any circumstances as this would be construed as abuse.

Pamela (care worker) *We need to respect, you know in our training, we have a training, abuse if the resident refuse what they want, we respect it,*

This was in contrast with the idea that someone with capacity, Laura, could have her movements restricted for her own safety. There was no mention of capacity, nor was there any discussion of the possibility that not giving care could be construed as neglect.

There was generally a view that ways had to be found to persuade residents to agree to necessary care. Although it was never voiced explicitly, staff reports indicated that it was considered important that residents retained some control over their situation. A common response to a resident who was refusing care was to leave them, for a while and try again later as is illustrated in the example below,

Hope (care worker) *You go and leave them and go, maybe when you come back their mind calm down.*

As Maria said in this example, patience was considered important.

Maria (care worker) *...patience is very important. It is very important in this kind of job.*

The example below demonstrates another technique identified by a care worker, on returning to the resident after care had been refused, she engaged him in conversation about things that interested him.

Teresa (care worker) *...what we did, we just talked about the football, about the TV programmes and then he cooperated.*

The value of explaining to residents what needed to be done was identified by most staff and is evident in this example.

***Maria (care worker)** Because sometimes they will say yes, but by the time you pour them with water they will resist now. There are problems like that but you just explain to them or just encourage.*

Staff were seen to be working to provide care with the minimum of restriction to residents' freedom. They put effort into getting residents' consent wherever possible. The techniques they explained showed evidence of their training and sharing of successful methods. I also observed staff consulting others for advice, not only care workers consulting nurses but care workers consulting their peers, especially where another care worker was known to have a good relationship with a particular resident.

There were times when the clearly expressed choices of residents who staff accepted had capacity were not respected. The example of Laura being prevented from leaving the home alone was one of these. The following two examples relate to the belief of members of staff that their decisions would have put residents at risk. The first was about a situation where a resident with capacity who was diabetic requested sugar in his tea. In this example this staff member said that she would explain to the resident why they should not have sugar, offer alternative sweeteners etc.. But if the resident still requested sugar she would have refused.

***Julia...**if they do actually understand but they still say "I'd like sugar in my tea",*

***Gina (care worker)** Well they can do,*

***Julia** You wouldn't give it to them even if they were cognitively able,*

***Gina** No, no you can't definitely not, no,*

This care worker was concerned that the resident could come to harm if they deviated from their diabetic diet. She was also stating that she could not disobey the rules as she believed she would be blamed for her action especially if harm resulted.

The alternative approach used by Janine (registered nurse) was to enrol relatives, possibly not giving the resident all the information but allowing them to believe that they had got what they wanted.

***Janine** Actually, you know, we are asking the relatives if... Like our one of the residents, you know, she love chocolate and she's diabetic. So the daughter, they are bringing this sugar, yeah. What they will do because she will not tell that, "oh this is the proper sugar" because they're bringing this one in like this as well. So we are giving that one, you know, but oh there is the sugar already. Anyway the client will say, no, that is not their proper sugar, no, they are not telling like that, you know. As*

long as you are putting the sugar but that is diabetic sugar and the daughter, they are bringing this diabetic chocolate.

One of the relatives offered a different view outlined in this example.

Christina *And if it's a question of put someone to bed rather than mess around, you err, I say, I've never known anybody refuse anybody anything, you know and you do notice these things when you come in a lot.*

David had fallen out of a chair previously and I asked Christina if he was being kept in bed to avoid the risk of further falls. In fact she thought that some staff were taking the easiest option, explaining why some days he was up and others remained in bed.

In some of the situations considered above staff members appeared to consider that they would be held responsible and blamed for deviating from the rules especially if the resident came to harm whether or not residents had capacity to decide to take the risk. However, this paternalistic approach, for example, withholding some information, was done with what the staff considered the best interests of the resident in mind and to avoid confrontation.

5.4.4.2 Staff numbers

Staff members' time was finite and sometimes individual wishes were restricted by the needs of other residents. Staff numbers, or possibly staff willingness, were noted by some residents as barriers when they made a decision but felt there were obstructions which delayed them, or prevented them carrying them out.

Katherine *I often would like more showers than I get.*

Julia *How many do you get?*

Katherine *Not enough! And how to cope with that. Well asking, I've asked for more showers, and erm, and on the whole they're alright, 'we'll put it in the book'. Which according to {care worker} is not satisfactory. It's them getting out of it.*

Julia *So it hasn't really changed what happens?*

Katherine *No.*

The way that this request was dealt with was considered inappropriate by the resident and a staff member had agreed. Katherine was not receiving the assistance she needed to have more showers although she asked for them.

The example below shows a common, if rather resigned acceptance of a less than ideal situation.

Nora ...probably some of them don't do things the way I would like, but that's everybody's way of doing things, you can't expect them to run whenever you say, I need your help but they come when they come,

Julia Yes, so sometimes you have to wait a bit longer than you'd like?

Nora That's right darling, not too long but maybe a couple of hours or something like that you know, but that's normal,

Residents spoke with resignation as they perceived that either there was a shortage of staff or that staff were just too busy and it would have been wrong to keep them from other residents who also had needs. In the following example Karen decided not to ask for what she wanted due to her perception of a shortage of staff.

Karen Oh I have a shower, not as often as you'd want because there's so many people,

Julia Have you asked the staff if you could have more showers?

Karen Well they're all so busy here, but here, there's so many people, the nursing staff is not, err, how should I say, super abundant, you know, it's not enough,

Julia So you don't ask for more because you think they're too busy, is that right?

Karen Yes I could ask them if I wanted, but they give us a bed bath every morning,

The example below demonstrates a reluctance to tie up a busy staff member. Geraldine, aware that there was only a given number of staff on duty, was concerned about other residents with significant needs so did not always ask for what she wanted.

Geraldine And I can't really monopolise one person for myself because a buzzer could be going somewhere.

Julia So you don't think it's reasonable to ask really,

Geraldine No, I would feel uncomfortable,

Julia Yes, yes because you feel you'd be taking care away from someone else?

Geraldine I'm taking away, exactly!

What appeared to be consistent amongst residents was that if a resident requested something staff would do their best to accommodate them assuming they had time. However, it was rare for staff to offer more choices, particularly offers of extra baths and showers which were time consuming for staff with limited time. It did mean that only the more outspoken and assertive individuals were able to execute their decisions.

Both residents and relatives had perceived that there could be inadequate staff numbers at times. In general this was not born out in the reports of staff as in the quote below.

***Julia**...talking about staffing levels...*

***Janine (registered nurse)** Actually, the staffing level we are okay because before we are only five carers in the morning but we increase into six, yeah. So, two allocated upstairs and four allocated downstairs.*

I went on to ask about whether the staff numbers would allow residents' to have a shower as frequently as they wanted. This quote demonstrates that it can be difficult to deliver all the care a resident may request.

***Julia** And do you find, I mean, is that enough staff, for example, if people want to have a shower, you know, if you really wanted to have a shower every day...?*

***Janine** No, actually, no problem about the shower, because that's why we have our allocations for the individuals who will have a shower, because we cannot give shower in one day for all the residents, that's why we are allocated each day, you know, like that but...*

***Julia** Yes, so there's days allocated.*

***Janine** ...some people, it depends, you know, let's say some people they don't want to go for a bath, you know, so we are planning, so when is another time we can give, yeah. But the one is allocated for bath, you know, actually they are giving it, yeah, but those people requesting that I want to have a bath, definitely if they cannot give in the afternoon... No, in the morning, they can give in the afternoon.*

***Julia** Yes, so, I mean, if somebody really wanted to have a shower or a bath every day...*

***Janine** Yeah, no problem.*

***Julia** You feel you've got the staff to do that?*

***Janine** No, but the thing is we have to organise...as well, like this Kieran, at first he was having every day bath, yeah, every day, because of his skin. So they are giving in the morning, the following day not available to give in the morning because it's busy so they're giving in the afternoon. Until before he will go to bed as long as we are giving the bath.*

This report showed inconsistency in that although Janine said that they could have accommodated a resident's wish to have a daily shower, she was clear that they could not offer showers to all residents on a single day. The allocated days for showers reflected old routine practice. However, there was a demonstration of some flexibility in that showers could be given at different times of day and the need to organise the work load was emphasised. Nevertheless, as she talked of Kieran needing to shower because of his skin rather than because he requested it, this did appear to be more to do with staff perceiving a need rather than resident's choice.

5.4.4.3 Staff communication

A number of relatives mentioned that staff were not always able to recognise attempts at communication an example is given below. Christina talked about David having good days and bad days, where on the good days he was able to express some choices.

Julia do you think the staff appreciate his good days and bad days and adapt accordingly, to listen to what he wants?

Christina I don't think they can really, for the simple reason he can't make himself known. I said I was going to get him a card with yes and no on, {laughs}

She realised that he was not able to verbally communicate his decisions any more, but staff were not recognising his attempts at communication. From what Christina said it appeared that the attempts at communication David was making were poorly recognised by staff. My observation of David showed almost no verbal communication. However, he did sometimes indicate his wishes non-verbally. An example of what could be an expression of a preference through nonverbal signals is given below. Christina noted that David did not like to stay in bed.

Christina...he does clamber up the side,

Not all staff responded to David's actions which appeared to indicate that either he was reluctant to stay in bed or had other unmet needs. Staff varied and some were more aware of residents' needs and more able and ready to establish what they wanted. This variability was recognised by Carol in this quote. Carol observed that staff were individuals and consequently behaved differently from each other with some being more aware of residents' right to make decisions.

Carol I think there is that cross section which you get in any occupation and I think the same applies to the nursing staff, I think there are people who are perhaps more aware of people's right to make decisions and choice to make decisions than other people,

Carol noted that staff's beliefs and attitudes could have a major impact on whether residents were able to decide for themselves.

Residents could be disempowered by not having the information necessary to make a decision. In this example Queenie was not seen making the best decision because she had misunderstood what was on offer to her.

Patricia *I did fight to get her a bigger room, she had a tiny room which was dark because it was on the angle and no toilet or anything it was horrible, I mean you couldn't move it was like this, so I had a word I spoke to Len {holder of Queenie's Lasting Power of Attorney} about it and he said she doesn't want another room and what I discovered was, he had discussed it with her but she thought she was going to another home. Moving out of here and going somewhere else, she didn't want to go to another building.*

No one had checked that Queenie understood what was being proposed until Patricia visited and provided her with the appropriate information.

As evidenced in the example below, several of the residents reported that staff did not engage in conversation other than when carrying out care tasks.

Victor *Well with some of the carers, they don't bother to talk to me, to speak to me or anything no, they don't bother very much. But they're good to me, I'm not saying they're bad to me, they're good to me, they treat me alright. It's just that they kind of ignore me.*

There was a perception amongst some residents that this was because staff did not speak English as Geraldine says here.

Julia *What about your relationship with your carers? Do you talk very much to them?*

Geraldine *They don't speak English, that is the trouble, you can't talk to them.*

Observation and interviews showed that most staff spoke at least adequate English and many had an excellent command of the language. Very few staff members were Caucasian or had English as their first language and some had strong accents. Staff speaking together in a language other than English was not observed but as there were staff who shared a common mother tongue it is possible that residents experienced this at times.

The manner in which staff communicated was important to residents. There was a perception amongst some residents that staff had poor language skills, did not always listen to their point of view, or only communicated with them when necessary to perform a task. This left some residents feeling isolated and unable to communicate their needs and preferences to staff. Other residents reported that staff did listen and tried to accommodate their wishes, as long as they had time.

5.5 Advance planning decisions

5.5.1 Nominating proxy decision makers

This section considers the nomination of a decision maker who could make decisions after a resident had lost capacity. However, it also includes the support that some residents receive from relatives or friends to make decisions while they had capacity.

Nominating a proxy decision maker could enable a resident to retain a degree of control when they no longer had capacity. Residents had thought about who might be the best person to act as a nominated decision maker. The central issues were who they trusted and why.

When asked why they thought someone was the right person to make decisions on their behalf the person's intelligence and sense was often mentioned as in these examples.

Queenie Because he's a sensible man.

Nora He's a very smart fellow,

In both instances the residents trusted the person to both help them with decisions now and to make decisions on their behalf should they lose capacity. They were placing trust in their relatives and friends due to belief in their intelligence and capability.

As has already been discussed (see 5.4.1), Victor was happy to pass decisions to his niece Carol, although he had capacity, as he trusted her and had concerns about his own shortcomings. He considered Carol to be more intelligent and more able to decide than himself. Carol discussed decisions with Victor but he was keen to ask her advice and to follow it.

An example of trust in family deciding and feelings of safety is given here.

Iris but judging from the family and all that, you know, you feel safe in those sort of things.

Nora, in this example, echoed the thoughts of many residents when she links her trust in her son as a decision maker with both his knowledge of her and the love in their relationship.

***Nora** Well he would decide on things that would suit me, that's what he'd do, because he knows me and he loves me,*

No matter who the potential decision maker was, the theme of how trust develops over time was present. If anyone was to be a decision maker for them, residents thought the person should know them well and have shown their trustworthiness and ability in the past (although in some cases the doctor was exempt from these requirements due to his or her medical knowledge).

The appointment of a nominated decision maker was a decision that most residents could make but few mentioned it and most said they had not been directly asked by the staff. An example of staff's failure to ask about a nominated decisions maker is presented below. Norman had a brother and a niece who he wanted to make decisions on his behalf if he lost capacity. When he was interviewed he had been resident in the care home for two weeks and he was clear that during that time no one had asked him about a future decision maker.

***Julia** so have they asked you here about next of kin and decision making,*

***Norman** No, no,*

***Julia** So nothing like that's been asked,*

***Norman** Not to me anyway,*

Only one resident (Laura) said that she would trust the staff to act as a decision maker in the event of losing capacity. She was very relaxed about who would decide for her. She suggested that the home manager or the assistant manager could decide. When asked about her family she pointed out that her brothers, although she would be happy to have them involved in making decisions for her, lived too far away and were "getting on in years". Geraldine echoes Laura's reluctance to burden relatives with decision making.

***Julia** ...would you like your nieces to be involved in deciding if you were unable?*

***Geraldine** No I wouldn't worry those girls for anything.*

Laura was satisfied with the prospect of staff deciding on her behalf but Geraldine had reluctantly accepted the situation as she could see no alternative. When asked who would act as a nominated decision maker if she lost capacity, she said,

***Geraldine** I thought it would be the staff,*

***Julia** Yes, and are you comfortable with that?*

Geraldine *Well I know that's, that is when you come you're under the care of the management and you have to accept a lot of things,*

Julia *Yes, so you think it's inevitable,*

Geraldine *It's inevitable rather than...*

Laura suggested that she had a good relationship with staff, Geraldine spoke less favourably about them, so trust was significant in the willingness to let staff decide. The difference in these two residents' views and circumstances emphasises the heterogeneousness of the Home's residents.

Some residents had appointed someone with an LPA for property and financial affairs and/or for health and welfare as the example below illustrates.

Nelly Yeh, *my son has power of attorney, my daughter has, they make any big decisions that come along for me, they have to,*

Confirming that many residents had not spoken to their relatives about them becoming proxy decision makers, Jane had not spoken to her aunt, Ruth, about future decisions, even to clarify that she was the person to decide. Although they had not talked about advance plans for care or treatment she considered herself in a good position to decide for her aunt.

Jane *Well, no I haven't talked about it, but I mean I think automatically, I think she would expect me to make decisions,*

Ruth and Jane had a close relationship and Jane was Ruth's closest relative. Jane indicated that the assumption that she should decide was based on family history and behaviour.

Jane *Well we haven't talked about it but I suppose it's a family thing, you know I've seen her probably every week of my life and she was my mum's sister and I mean we're very, we haven't got any other family and we're just used to looking after each other...erm, well I'd like to say it's just what's best for her, but taking into account what, knowing her personality,*

She, similar to other participating relatives, did not appear to be troubled that these things had not been discussed before, nor did she think that this reduced her duty to be involved in decisions relating to her aunt. She believed that the knowledge of her aunt would allow her to make appropriate decisions on her behalf.

Many residents had not nominated a decision maker, formal or informal. Staff had documented next of kin in all residents' notes. However, it appeared that a conversation with the resident about who they would want to decide on their behalf should they be incapacitated had only taken place when residents were proactive.

Other advance decisions could be made about major issues related to residents, often around health care and end of life. They are sometimes made with the support of family and/or staff and doctors. They involve deciding what residents might like in the future when they lack the capacity to decide for themselves. This is included here as, like nominating a proxy decision maker it could allow residents to have control over what would happen to them after they have lost capacity. Others can make advance decisions for a resident after capacity has been lost to avoid crisis decision making, but this section only considers residents deciding for themselves with or without the support of others.

Staff and relatives fear of upsetting residents meant that conversations about advance plans for care and treatment especially at the end of life were rare. An example is given below.

***Ethel (registered nurse)** nurses make people to get better, not to die, this side of nursing, I never like it, so that is my way, but because the times demands that, you do it, but not my favourite thing.*

***Julia** so do you think that people are just reluctant to talk to residents because of fear of upsetting them about the end of their life?*

***Ethel** Yes, as some of them, people that I think are active.*

I shared this anxiety specifically because, as this was a research project, it was not going to affect their care or treatment and upsetting a resident would have been unethical. However, I found that as I led into the topic a number of residents made it explicit. An example is where Katherine, when asked about future hospitalisation and treatment, answered with,

***Katherine** ...what you mean whether we would want to be switched off?*

She was comfortable talking about the possibility of her death although she told me she could not decide and would leave that to her husband and children.

There was documentation in the residents' notes that a significant minority of residents, including some of those interviewed, had been spoken to about issues such as

hospitalisation at the end of life and preferences about resuscitation. In the case of Kieran, it was documented by the GP that he was not for resuscitation due to his clinical condition. This was later changed after a discussion with Kieran and his decision that he would like to be resuscitated was recorded in the documentation. Kieran's wishes had overridden that of the GP and staff members. This is discussed in more detail in the following chapter.

Residents rarely reported having discussed end of life decisions either with staff or with their relatives. As in this example, some suggested that they had just never thought about it.

Julia Is there something like I don't want to leave here now, I don't want to go to the hospital now, or would you want to go if you needed some treatment? Have you thought about it?

Nora Not really thought about it.

Here the resident was using humour as a defence to the idea that she had not considered any future illness.

Nora Never mentioned it {plans if ill in the future} pet, because I'm never going to be ill, {Both laugh}

Julia No, you're going to live forever aren't you?

Nora That's right darling.

Julia Good for you!

Nora You think you're going to live like this 'til the end of time.

As in the example below, other residents were clear that they had thought about it and knew what they would want.

Julia ...if you were really acutely unwell would you want to go to hospital?

Geraldine Yes.

Julia Would you prefer to stay here or,

Geraldine I'd prefer to go to the hospital.

Julia ...have you told anybody that?

Geraldine Oh they know, they send you, there's no mistake about that. If you're not well they send you to the hospital.

Julia Yes, so you feel there's no need to discuss it because that's what would happen anyway?

Geraldine Yes, I wouldn't want to be stuck up here,

Julia Yes, that's very clear, erm, but there's never really been a discussion about it.

Geraldine No.

Julia No real advance planning of any sort of what would happen if,

Geraldine No.

Geraldine had not discussed this with anyone as she believed that the home's default position was to send residents to the hospital if they were unwell and as this concurred with her wishes she was unconcerned that advance plans had not been discussed with her. I asked her whether she would like to make an advance plan but she thought no one would bother, not considering it important.

Julia And have you ever considered writing down what you'd like?

Geraldine No, who'd bother? I don't think anyone, I don't feel that anyone would bother.

Julia You mean that residents would bother or that the staff would bother or,

Geraldine I don't think anyone would bother.

A number of residents reported that they had not been asked by staff about any advance decisions about care or treatment as evidenced below.

Julia ...have they asked you about if you were ill and had to be hospitalised or anything like that, have the staff asked you about any of your future plans,

Katherine Yes. I'd rather come home if I don't know if they like to nurse people to the end, I rather gather that they probably send people to hospital,

Julia Yeh. Have you talked to anybody about it?

Katherine No. Nobody has had time to talk to me.

No one said that they had made any formal advance decisions.

The need to have control was demonstrated in the proactive decision to make future plans independently of the care home staff as illustrated below.

Geraldine And I've already made arrangements for funerals and everything. All settled.

There was a mismatch between the dialogue around the "Gold Standard" framework (National Gold Standards Framework Centre 2010) and what was reported by residents. Some decisions and reports of conversations had been documented but it appeared residents either did not remember or did not understand what had been discussed.

5.5.2 Relatives view of advance decisions

Some relatives did not consider advance decisions to be necessary or appropriate as the example below illustrates. Heather (relative) was interviewed together with her sister in law Iris, a resident, when asked whether any advance plans had been made she said.

***Heather** No I don't think so. We're involved in the present day rather than the future. We'll cross that bridge when it comes to it I think.*

Perhaps one of the simplest examples of why advance decisions had not been made by this generation was that in the past it just was not done as was said here.

***Julia** But it's not something you've ever wanted to give much thought to, advance decisions about your health?*

***Heather** We didn't did we Iris? In our time.*

***Iris** No,*

***Heather** We just did it as it came along didn't we, decisions were made as and when necessary.*

***Iris** Still does, you don't provoke them! Perhaps we should have done but, {laughs}*

***Heather** I don't think either of us are that well organised are we really? {laughs}*

***Iris** Probably not, no.*

Heather's use of humour may have been showing her uneasiness at discussing a topic which made her feel uncomfortable. Iris by this time had quite advanced dementia so it would have been difficult to ascertain her wishes about serious issues such as health care or end of life.

Christina had not discussed what David would have wanted in the event of life threatening illness. She did however believe that she knew what he would want. However, she had never discussed this with the staff. Few relatives had proactively approached staff to discuss future plans appearing to think that the decisions could be made when the situation arose.

Carol held an LPA for both health and welfare and property and finance although Victor had capacity. Unlike most other relatives interviewed, she had raised the question of future medical interventions with her uncle. They had discussed what he considered to be a minimum acceptable quality of life. Thus, if he fell below this any major intervention would be inappropriate.

***Carol** Yes, I have, I've talked to him about, about not a living will exactly but spoken to him about whether if anything where he was bedridden, and I did say this to the doctors as well, that if he was bedridden and incapable of making any decisions at all, about whether he wanted to be outside or whether he wanted to be inside or whether he wanted to be out of bed or in bed and that whether he'd want to go on and he said no, so I do have that in the back of my head because it would be down to me to make that kind of decision,*

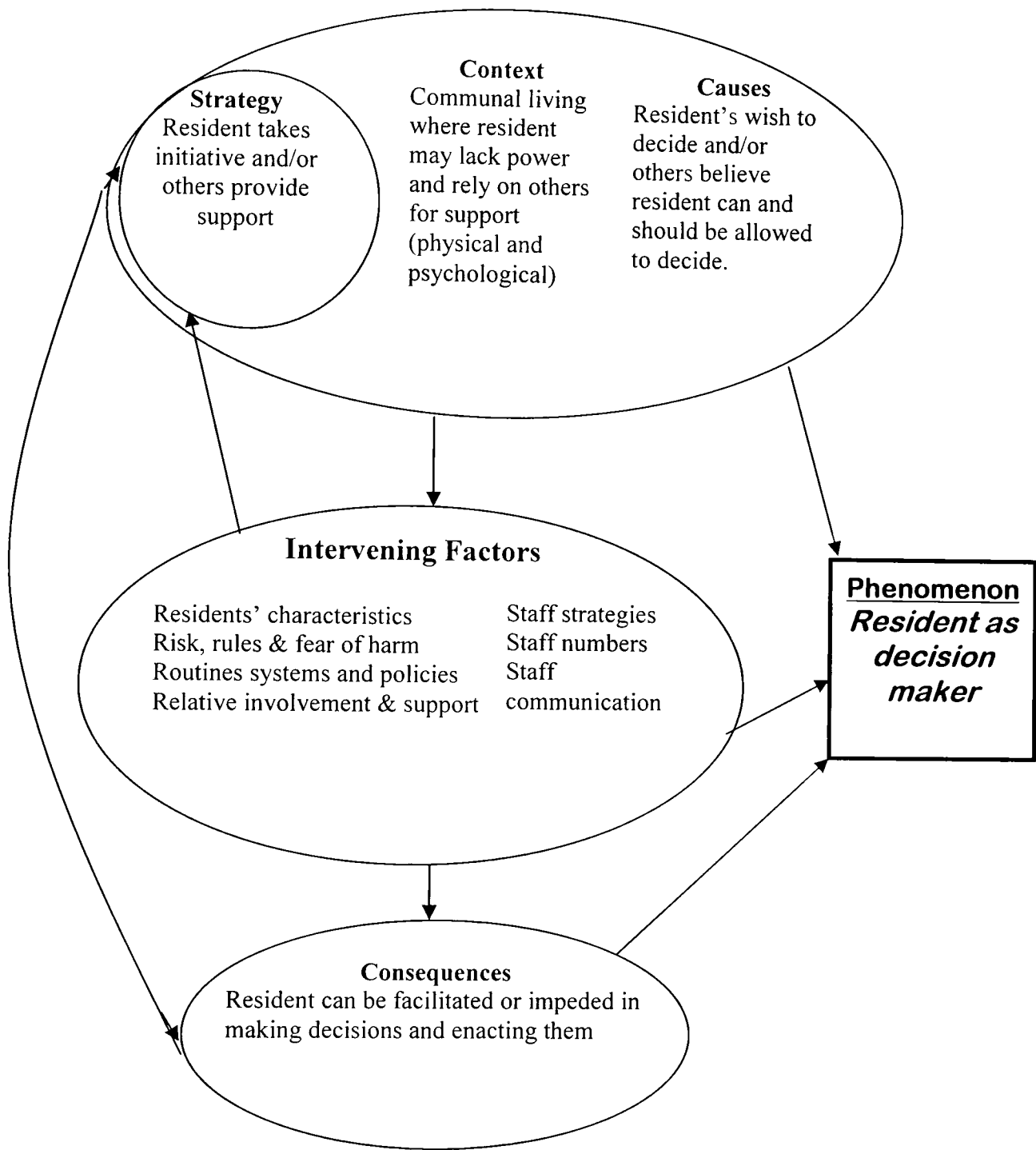
Few residents or relatives talked of having made any advance plans about future illness or end of life. In many cases there was a reluctance to discuss these issues. There was generally a feeling that this was not important and did not require immediate attention. Residents seemed mostly content to leave decisions to others when the situation arose, and relatives were largely reluctant to grapple with these difficult issues before necessity forced them.

5.6 Summary

This chapter presented the first central phenomenon of the study: the resident as decision maker. The findings show the factors that empowered or disempowered residents in making and enacting decisions. The need for care put residents in the power of others as they needed assistance to enact decisions. However, there was evidence of residents claiming power and control as well as staff using power to ensure the enforcement of rules and to avoid risk. There were examples of negotiation between some staff and residents where residents made decisions to take risks but these were not frequent. Relatives were often seen to empower residents, acting as their advocates and assisting them to make and enact their own decisions.

The findings have been presented in the paradigm model suggested by Strauss and Corbin (1998), see Figure 1 below.

Figure 1. Central Phenomenon 1: Resident as decision maker



This model provides a summary of the central points discussed above. The components of the paradigm have all been discussed in this chapter. The two sections, views on what is a decision maker (5.2) and when a resident decides (5.3) related to cause and context, although these elements are also discussed throughout the findings. The intervening factors are closely related to the facilitators and barriers. Both strategy and consequences were derived from the holistic picture of the findings presented in this chapter.

The following chapter will consider the second of the phenomenon identified: others decide for resident.

Chapter 6

Others deciding for resident

6.1 Introduction

This chapter considers the findings concerned with the second of the two central phenomena: others decide for resident. This was either at the resident's request, due to a lack of capacity, to protect the resident from harm, others believed they knew best or they were merely taking the easiest course of action. This particularly addresses the research question; Who makes the decisions, with what authority and/or responsibility? The chapter discusses, first of all the different grades of care home staff involvement in decision making, then the relatives' and finally the doctors' involvement. The paradigm model of this central phenomenon (Strauss and Corbin 1998), built from the axial coding has been employed and is presented in Figure 2 at the end of this chapter (6.7).

6.2 Staff decision making

The open codes relating to staff decision making can be viewed in appendix K, Table H. The debate as to what constitutes a decision was evident in staff interviews as it had been in both interviews with residents and their relatives and friends. This was particularly true for care workers.

A number of care workers interviewed said that they did not make decisions as they considered that this was not within their role and this is illustrated in these quotes.

Hope (care worker) I can't decide for myself, or as a carer you can't decide for yourself,

Maria (care worker) Yes, there's also limitations with my role, my job description.

The type of decisions care workers made were limited by their role but it was often hard for them to recognise themselves as decision makers although their actions could be very important to residents. Most of the decisions they made were "everyday decisions". Their role did not involve formal risk assessment, care planning or decisions about treatment. Consequently, many saw themselves merely as followers of instructions. There was a lack

of recognition of the decisions involved in how they carried out instructions and delivered care and their level of flexibility and responsiveness to the needs of residents.

Residents, relatives and registered nurses nevertheless recognised that care workers made decisions about everyday issues, usually while giving care. From the residents' point of view it was noted that they were often dependent on staff to carry out their decisions due to their physical disabilities.

6.2.1 Residents with dementia and cognitive impairment

The majority of the residents, whose friend or relative were interviewed, had dementia, some with severe dementia. Therefore it was a frequent theme that many residents could make very few if any decisions themselves. Staff made many of the everyday decisions. As in the example of Derek who told me that the care workers made everyday decisions for his mother.

Julia ...what about small decisions?

Derek No the care worker does all that.

This was confirmed by residents with some stating that certain issues were decided by staff as shown in this example.

Julia ...what about showering and bathing, do you decide when you'd like that done?

Queenie They more or less decide.

Julia And it's the carers who look after you day to day who decide really?

Queenie Yes

My observations showed that there were allocated days for people to be bathed. The resident was told that it was their day for a bath and asked if that was acceptable. Most residents were compliant. If a resident refused a bath or shower, a strip wash was offered. Where residents requested a bath when it was not their allocated day, staff usually explained that tomorrow was their day but they would give them a wash today and this was normally accepted.

The example below demonstrates that although residents were generally compliant they might not have considered the situation ideal. Queenie said she was not unhappy with staff deciding but when I commented that she was easy going she said,

Queenie Yes, too easy, too easy going.

Staff did not always pick up residents' nonverbal cues and this is illustrated here. Molly said that her mother was no longer able to make any decisions even to go to the toilet.

Molly *Whenever I've been around and they've asked what she wants for tea or what have you, she's ummed and arred to such an extent that they sort of decide for her. Based on what she's had at previous times which is not always the right decision, because I've seen her long for something somebody else has got. So when I've been here I've said you know she will have baked beans or she'll have pasta so now they do give her the baked beans or the pasta where previously they were always just giving her sandwiches and I noticed she was tired of them from the chewing point of view even the swallowing point of view,*

The staff made considerable effort to accommodate the residents' wishes while most realised residents needed a minimum level of care even if they were reluctant. This demonstrated the conflict they felt between their duty to act benevolently in the residents' best interests and the need to respect their wishes and allow them choice. They generally tried to use the least restrictive methods to achieve their end as the Mental Capacity Act (MCA) (2005) dictates. They sometimes had to face the difficult situation where a resident constantly refused assistance with personal hygiene although I only observed situations where the carer was able to persuade them reasonably easily as illustrated here.

From field notes 1015 15/07/10 *Ilene was sitting in the lounge. Teresa (care worker) went to her and said "It's time for your bath Ilene". Ilene said she didn't think so, she was dressed now. Teresa explained that it was a week since her last bath. Ilene said "don't bother me now, tomorrow will be better". Teresa sat down beside Ilene and told her that she had time now and probably wouldn't tomorrow so it would be better if she came now. Ilene gave a big sigh and got up saying, "I suppose you'll give me no peace if I don't". They both laughed and walked off arm in arm.*

The quote below further indicates the difficulty when a resident refused care.

Janine (registered nurse) *Because when it's time for washing and dressing and she's not very, very co-operative, you know, she's very restless, she's agitated, especially when you're holding her and she's smacking you... She's very hot tempered as well because even to the relatives, she's trying to hit the residents, you know. So when you are washing and dressing because, of course, you have to force to wash and dress her because she's already fully wet. Just okay, so we are holding them. Definitely we have to change her, yeah, that is the problem but the thing is sometimes when you're doing her, she's shouting too much as if you are doing something to her, you know, so that is not as well good when somebody's hearing,*

that somebody is shouting, as if you are doing something to her, that's why she's shouting.

Julia *Generally one of the trained staff, one of the registered nurses would go in...?*

Janine *Yeah. That's what always we do. They are doing and one are explaining.*

"Oh Sara, just one minute only, they will change only your pad so that it's dry and you will be comfortable". That's the only thing we can do, nothing else, after that, as long as she wants to lie down on the bed, only as long as she's clean already, I don't mind.

Staff inevitably felt uncomfortable when the resident was strongly physically and verbally resisting care. However, as this resident had severe dementia and was incontinent she could not have been left for long periods without this care. Observation had shown me that Sara could be very volatile and I did see her being physically aggressive towards other residents on more than one occasion, suddenly, and as far as I could see as an observer, without provocation or reason. Care workers often passed these situations over to qualified nurses. I did not witness intimate care delivered to any resident when they were resisting as I felt this would be unethical as I would have been unable to gain consent or assent from the resident. Janine went some way to explaining the oft expressed frustration when residents were difficult to care for and how patience and persistence had to be applied.

Janine (registered nurse) *But it's very difficult here in the nursing home, you know, dealing with the clients, especially those people who are not very co-operative, it's really very hard to give this high standard of care for them. But there is a time so in whole day we are trying, you know, we come back.*

Although most care workers generally said they would not give care against a residents' wishes, in this example Anna took a more pragmatic approach recounting when she had decided it was necessary to deliver care although the resident was reluctant.

Anna (care worker) *I believe that by that time the person has gone months and months without, you can decide OK they're not really giving their consent although it's their right but then again at the same time it's erm, they have to be clean or maybe there you can decide that OK, Mr so and so you explain then you tell them OK you're going to have a bath because it's been quite a long time since you had a bath and you really need to.*

It was noticeable that no care worker talked about mental capacity and most registered nurses either did not mention it or only in passing. Therefore there was little discussion on how this affected care delivery when residents refused care. One of the few examples where it was mentioned is given below. Marga (registered nurse) talked about mental capacity and told me that the MMSE was done on admission and if necessary a mental

capacity assessment would be requested. This example was about Kieran who was refusing medication.

***Marga (registered nurse)**...we knew that he had the capacity but we need to prove that he has capacity to make the decision, so obviously we referred him...she {the doctor} assessed him and said "Yes, he has the capacity". Because he was refusing we really don't know what to do because he should take his medication one way because of his problems and the one hand that is his choice whether to take it or not, we can't even force anybody to do anything, so we knew that he has capacity to make decision but we need to really prove.*

***Julia** And then, after that, if he refuses, okay?*

***Marga** That's fine because if somebody has capacity then that's fine, no problem. If a person doesn't have capacity then we need to involve people otherwise, you know, that if "I have capacity, if I don't want, I don't want," you know that's their choice.*

It appeared here that there was fear of blame. The mental capacity assessment appeared to be defensive practice based on the need to have evidence to support their actions if anything went wrong.

6.2.2 Decisions on hospital admission

Qualified nurses were involved in deciding whether a resident should be admitted to hospital in the event of illness, categorised as "infrequent decisions".

Staff did not always inform relatives prior to a resident's hospital admission as demonstrated in the example below. Hospital admission was considered essential by this staff member, so she did not contact the relatives first but provided them with a *fait accompli*.

***Janine (registered nurse)**...definitely this person is ill or whatever, we will send in the hospital without the relatives knows, yeah, and then after that we will call the relative that we send in the hospital, you know, because he's like this,*

The example below confirms this.

***Christina (relative)** Just over night once, twice it was his catheter, the third time, I think it was his cough you know.*

***Julia** Ok and do they ask you before, or do they just tell you he's going?*

***Christina** He was gone, you know what I mean.*

***Julia** So he was already on his way by the time you heard about it?*

***Christina** Oh yes.*

Christina was not unhappy with this although she had not been asked whether she would want to be called in such a situation. She was more concerned that the 'right'

decision be made. However, these were not acute emergency situations and it would have been possible to consult Christina before the hospital admission. David lacked the capacity to make the decision about the admission himself so staff and possibly the doctor were deciding.

When staff considered the resident's decision to be unwise they contemplated why the resident was making this decision, in this case refusing to go to hospital when the doctor had recommended it, they would also often involve relatives.

Abeo (registered nurse) ...doctor says send her to hospital, they {the resident} decided not to go, if they are saying "no I don't want to go to hospital," then what is the reason, if they've got something, why you don't want to go to hospital? Why are you feeling what happen, then you explain why she is going to hospital. But if she is not we involve the family,

It appeared that relatives were involved to try and change the resident's mind to comply with the staff and doctor's view of what was in the resident's best interests. The quote below appears to indicate that relatives would be asked to overrule a resident's decision if staff considered it unwise. The decisions were based on the best medical interests of the resident.

Julia If somebody's deteriorating here and they're still able to tell you and they really don't want to go {to the hospital}, you won't send them?

Janine (registered nurse) Yeah. We will...That's why we're always involving the relatives.

Other relatives expected to be called regarding medical treatment, including in an emergency. In Derek's case he had been called when his mother fell.

Julia They would call you before taking any action?

Derek Yes, always, once or twice she has fallen they have always called and I have come.

Staff contacted Derek before a hospital admission but not Christina. This may have reflected Derek's more assertive manner with staff, enabling him to have more involvement.

6.2.3 Collaborative decisions

Collaborative decisions with the involvement of a team of professionals were frequently considered for more major decisions, both infrequent and advance decisions to decide what was in the resident's best interests specifically where a person lacked capacity to decide for themselves, this is illustrated below.

Marga (registered nurse)...they {relatives} cannot make any decision because obviously the GP will be involved, all the professionals who are really looking after the person, they will be involved because everybody will have their chance to, then it come to the conclusion that when it really... everybody feels like that, what is best for that client that will be really we will follow because we are not really able to make our own decision neither the next of kin.

Marga told me this collaboration came from adherence to the MCA (2005). She reported that all staff had training on the MCA and the Deprivation of Liberty Safeguards (2005) but this was not in evidence from other staff's reports.

The inclusion of all the people involved in a resident's care and their significant others, regarding what was in the best interests of a resident who lacked capacity, inevitably led to conflict at times as the example below shows.

Marga talked of a relative who was insisting that a resident be admitted to hospital when this was considered inappropriate by the team. The staff had involved the GP, the palliative care team and a psychologist and there was agreement that a hospital admission was unnecessary, clinically inappropriate and would not be in the resident's best interests. The resident had initially said that she did not want to go into hospital but it appears that she changed her mind when her son arrived.

Marga (registered nurse)...first of all she said she don't want to go, then when the son came she said she want to go to the hospital, at least she want to please her son.

There was a distinct suggestion that the resident had been coerced by her son into changing her mind and requesting that she should be sent to hospital. Other family members were against hospitalisation, agreeing that little could be done. However, ultimately the team agreed to hospital admission due to the persistent insistence of the resident's son. After it had been explained to the resident's son that any attempt at resuscitation would be very unlikely to succeed, he appeared to accept that this was the case but still wanted her to be hospitalised and resuscitation attempted.

Marga (registered nurse) he said "Sorry, I don't know whether my mum might die but rather I could do everything best for her then I no need to worry afterwards".

This appeared to be against the resident's best interests. The son who was insisting on the hospital admission was concerned about how he would feel if his mother died and he had not obtained all the treatment possible rather than his mother's best interests.

Another example was given, this time in relation to insertion of a feeding tube, where relatives' decisions appeared to go against appropriate clinical practice and the resident's best interests. The resident showed signs of distress and staff said they found this situation uncomfortable. The reason for the family insisting on enteral feeding has been mooted by the staff nurse here.

Marga (registered nurse) ...they thought that because the miracle is going to happen, she's going to get up one day, that was in their mind.

Marga saw the relatives as unrealistic despite the attempts to explain the situation. She, along with other professionals involved, considered this intervention to be futile and rather than extending life, as prolonging the dying process.

There was concern amongst staff about risk when a resident becomes unwell and staff considered they needed hospitalisation. If a resident refused to go to the hospital staff would attempt to encourage and persuade them this is demonstrated in this example. Janine (registered nurse), when talking of how she decided whether a resident should be hospitalised, talked purely of their medical interests considering the clinical signs and symptoms. Once the clinical decision was made, as long as the resident did not refuse, no further consideration was given.

Janine (registered nurse) I told Eddie, if you are not become okay I will send you into hospital right now because look, you're not responding" "No, I'm okay", I tell "no you're not okay actually, but anyway I call the ambulance, you know, to see you first". Yeah.... Even then, you know, that the resident like Eddie, he said, "no I don't like", I told, "no, you have to because they will monitor your blood sugar because it's too high", it's showing a high index, so we don't know, maybe forty or fifty. so we don't know, we cannot tell. So that's why I'm saying because that is a risk but we cannot keep you here but in the hospital there's a lot of emergency that they can give there.

This example shows that due to concern for the resident's health, at times, the staff may have put considerable pressure on the resident to agree to hospital admission. In this exchange it appeared that the resident was not given the opportunity to refuse.

6.2.4 Decisions on medication

Administering and taking medication was an everyday decision, while prescribing of medication was an infrequent decision.

Some of the residents had responsibility for taking their own medication, although as this example shows staff felt it necessary to retain control. This part of the interview followed a discussion about capacity with Marga accepting that these residents (Rita and Geraldine) had capacity to manage their own medication. However, she identified that there was covert monitoring of their medication compliance.

Marga (registered nurse) ...because one thing what we do, the girls go and check the medications that really they are taking or they're leaving it somewhere else, you never know with the memory sometimes, they can be very good but at times, you know, they might be forgetful and it's because they are really reaching that stage, isn't it? Well we normally check the medications and they know that they are taking it. Sometimes they just sign the medication time itself, they just go and just have a chat with them and just observing without their knowledge that they are really taking it or... but they are fine at the moment and I normally... so I know that they are taking it you know, that I think every week they'll just make sure that really they are taking it.

Both these residents had MMSE scores of 29 and there was little evidence that they were forgetful. There were other situations where a resident was covertly observed against their wishes in relation to other risks such as a resident at risk of falling who was observed when she left the Home. Although they did not question this resident's capacity to decide, staff were compromising, they perceived that residents would have a freedom to act as they wished without restrictions, whilst the monitoring reduced the risk.

6.3 Advance planning: the staff perspective

This section considers advance decisions in relation to illness and end of life.

The Gold Standard Framework Centre (2012) for people nearing the end of life was talked about by a number of respondents. The way this is implemented is explained in this example.

Ethel (registered nurse) *The death is expected, so then we have to do the care plan for that person and then we involve the residents, their relatives and there are some sensitive questions to ask. So when they give us the consent, from then on, some although expected, but maybe months or weeks or day or whatever.*

A reluctance to discuss end of life issues early was identified as is evidenced below. I questioned whether staff discussed with residents their wishes about end of life while they were well.

Julia *They're still well.*

Janine (registered nurse) *We will not talk about that. But when the condition change, that time we will start and involve the relatives as well.*

Julia *Okay. So, if something happens suddenly, if somebody suddenly collapsed, they will be transferred to hospital...*

Janine *Oh yeah. Definitely.*

Julia *...because it won't have been discussed before?*

Janine *No, no we have to transfer in the hospital.*

This quote suggested that little advance planning was done while the resident was still able to participate and decide for themselves. Only at the point where the resident became ill and appeared to be entering the 'end-of-life phase' did discussion start. The relatives were involved at this point and this appeared to be routine regardless of the residents capacity. As Geraldine (a resident) suggested, (chapter 5, 5.5), there was a default of admission to hospital unless the person is on the "Liverpool Care Pathway" and relatives (rather than residents) have agreed that hospital admission was inappropriate.

If an advance decision had been reached and documented staff appeared to be comfortable with deciding not to send a sick resident to hospital as demonstrated here.

Janine (registered nurse) *But because the relative's already signed. But if something happen, you know, we don't want to send her in the hospital. So definitely we are not sending in the hospital, at all, because somebody already signed.*

Once the decision to not hospitalise had been documented and signed by a relative the staff member no longer considered the clinical appropriateness of the admission or assessed the risk.

There were examples of residents who had requested to be resuscitated in the event of a cardiac arrest against clinical opinion. The staff explained to the resident the almost certain lack of success of the intervention but if the resident still wanted a resuscitation attempt this was respected.

Marga (registered nurse) ...if the resident, that is people to respect the resident, like Jack, we knew that it was inappropriate that because he insisted, he said "This is my life, I know that because I might die or I might live but you can't make decision, it's me", because Jack, even sometimes he can't even talk properly and he was in a very bad state and I said "Do you really know what you're talking?", he said "I do know what I'm talking, I want to be resuscitated", I was there and the doctor also was there and he said "Are you sure, and being a doctor I am telling you that you...because there is no quality of life and why really do you want to suffer and struggle with these all things in the ICU?", he said "I like to be like that, what is your...", so he said "What do you want me to do?", I said "If a client is really that insisting then well...", if it was somebody else that's different, but if a person is telling like that we need to respect their decision, even though most don't say but very rarely you can hear from people like that, "I want to be like that", that is only I heard from Kieran and Jack,

If residents had the opportunity to make decisions in advance of a crisis this might have enabled them to retain control even when capacity was lost, whether due to dementia, acute delirium or reduced consciousness.

6.4 Authority for and underpinning values in staff decisions

Staff, including care workers, at times were obliged to make everyday decisions for residents who lacked capacity. However, they had no authority to decide on behalf of anyone with capacity. They recognised a duty of care owed to residents and this was sometimes interpreted as a duty to protect those with capacity from taking risks of their own choosing. As the example below indicates, staff often saw compliance as consent and believing that that was the only authority they need.

From field notes 0910 23/06/10 I was sitting with Iris while she ate her breakfast. Hope (care worker) came in and asked if she had finished. She said she had and Hope said it's time for a bath now. She busied herself getting Iris's clothes together and then said "Come on then", Iris got up and followed her.

It was generally quite difficult to establish what values underpinned decisions made by the staff for residents. There was the difficulty that, for many of the staff, English was not their first language thus, it was not easy to reach understanding on such complex issues. However, the English language was not the only problem as a number of native English speakers could not answer these questions. Generally a question about the values behind the decision was answered by concrete information about how a decision was made, as in this example.

Julia so can you think when you have to make a decision, for example. admitting somebody into hospital, what sort of values or principles underlie your decision making?

Ethel (registered nurse) Like what happened to us, we came on duty and one of the resident was sick, my colleague told me he's been vomiting, I went up and I did observations and with my experience, I saw that a person with a temperature up to this, then it needs to go to hospital. He's got 41 BP, high and then going down, you can't even get a diastolic, so I read in the care plan it's not told there that you know shouldn't be admitted, so we dial 999.

Ethel is talking of making a clinical decision, although the final decision was based on whether an advance decision had been made.

Staff often said that they considered it the right of every resident to make their own decisions as in this example.

Chrissy (registered nurse) I would like to think that everybody has the right to choose for whatever they want,

Abeo suggested that these rights came from legislation such as the Human Rights Act (1998) and the MCA (2005).

Abeo (registered nurse) Under the rules that everybody has got rights to take that decision. Legislation. Human Rights, and also the Mental Act came which was the help people decide, how we are going to follow.

Although legal rights were often mentioned, only one staff member mentioned the Deprivation of Liberty Safeguards which were potentially relevant to many residents as they had cognitive impairment.

Undertaking risk assessment was identified as a way to make decisions as in the example below.

Julia...what sort of values or principles underlie your decision making, how do you make the decision?

Marga (registered nurse) when we make a decision sometimes we go to look through the risk, whenever we are doing something always we do the risk assessment, so it depends upon the risk.

Julia And what sort of risks might you be talking about?

Marga There is a lot of risk, you know, because sometimes it could be medical, sometimes it could be mental, sometimes it could be physical, you know that whole area we have to look, so if we do that how it will happen, what will be the outcome....

After this Marga went on to talk about the procedure, who would be involved in the decision and how the decision would be communicated to all concerned. I found it very difficult to lead participants away from the concrete towards the philosophical.

The quote below suggested that rather than carefully making decisions with specific principles in mind, a crisis was reached and then action had to be taken quickly and by this time there was little time for deliberation.

***Julia**...can you identify the principles or values that underlie how the decisions are made or who makes them? Why you do it in the way you do?*

***Abeo (registered nurse)** Sometimes it's not that you think about it, it just comes like that really when it's a situation like that and we think what are we going to do now? Oh my God the situation has gone so far like that, that situation has gone that far.*

There was no evidence of reflection after the event to see what values were employed at the time, or which might have been employed. It seemed that decision making in a crisis situation was considered the norm and no action to change the process had been considered.

Best interests, the principle on which decisions must be made according to the MCA, were discussed throughout 6.2 above. This was an important basis for decision making by staff, although it appeared that it related to residents' clinical interests rather than a more holistic assessment of the person.

The benefit of others was also considered as each resident was one of many in the group home, this is illustrated in this example. The resident mentioned lacked capacity so care could be delivered on the basis of best interests (MCA 2005) if, in fact, it was in her best interests.

***Anna (care worker)** There is this situation whereby, OK we've had a lady before fine, she had dementia but she used to very, very incontinent, very incontinent, to the extent that no one would really stay near her and when you talk about bath she won't like it. Yeh, that's why, that's a bit difficult, but then she really has to be clean so that she can fit in the society and just make the environment and herself clean as well.*

It is likely that a bath would have been in this resident's best interests and appropriate under the staff's duty of care. However, where there is communal living, Anna understandably considered the other residents to whom she also owed a duty of care.

If a relative was very assertive and had different opinions to the resident, the staff sometimes allowed their wishes to override that of the resident's and to override the resident's best interests (see 6.2.3). Staff felt they needed relatives' permission before deciding not to admit a resident to hospital if they were seriously ill. This reflected the fear that they could be blamed for an untoward event. This fear was reflected in the interviews and behaviour with all grades of staff exhibiting a general risk aversion. More reflection and analytical problem solving was evident from some staff but without mention of a resident's capacity to make specific decisions.

6.5 Relatives and friends decision making

Relatives varied considerably in their involvement in decision making regarding the care and treatment of the resident. Some of the facilitators and barriers to, and motives for relative involvement are discussed below. Relatives often talked of residents' inability to make decisions and said that most everyday decisions are made by care workers. Many relatives were happy with this situation but some would have liked more involvement.

It was difficult to assess which were the most important decisions for relatives. Most relatives only discussed everyday decisions when prompted, where infrequent decisions, particularly about health care and treatment and finances were raised spontaneously.

For example, Derek said that his mother was unable to make decisions on her own behalf any more (see 6.2.1). I asked him whether he got involved in the smaller decisions about Eleanor's life and care but he said that he left that to staff.

However, he visited daily and stated that he would inform staff if he thought there were shortcomings with his mother's care. He considered it unimportant whether he was consulted over everyday care issues, his priority was that he should be contacted if a medical decision needed to be made. Unlike most residents, he considered infrequent decisions to be more important than everyday decisions.

Heather (relative) was asked if she thought that Iris had any unmet needs. She focused on everyday issues.

***Heather** Well it would be nice to know what clothes you might need and that sort of thing, shoes maybe, sandals that sort of thing.*

This is an example of where relatives placed importance on small issues that affected residents' lives. Due to the resident's dementia she was unable to tell her relative what she needed. Consequently, the relative looked to the staff to provide this information, but in this case there appeared to be a lack of communication.

Some relatives talked of their involvement in everyday care for their relatives. Molly had talked about washing her mother's hair and I observed Derek helping his mother with her dinner most days. There was evidence of a desire to help with everyday care in most interviews. Although the desire to help was common the example below showed that this could be problematic if relatives are not informed about the care.

***Christina** I don't know if I'm doing the right thing, it's like yesterday I gave him a drink and I said, I was telling my daughter last night, and she said did he have the stuff in it? So I said no he just had a drink and then he started to cough rather badly, and she said it's your fault and I thought "Oh dear I've done it all wrong", but he seemed to want a drink badly,*

David was on thickened fluids due to swallowing difficulties. It appeared that Christina did not understand the reasons and implications. This was emphasised with her concerns about the unappetising food, he was on a diet of liquidised food.

***Christina** But now he seems to be into pap all the time. You know pappy food. There again, it could be a psychological thing that he doesn't like, doesn't like pap.*

It was of great importance to Christina to see David with appropriate food and drink. As she said, she always used to make sure he had a good meal and a cup of tea when he needed one. Her lack of understanding was making food and drink a considerable concern for her, and there was little evidence of understanding about this from staff.

Although emphasis was often placed on the importance of medical decisions, relatives did not always consider that they needed to be involved, this was considered in 6.2.2 above.

There was an acceptance among some relatives that hospitalisation was a default position that did not require discussion as it was what they would have wanted anyway, this echoed opinions expressed by some residents (see chapter 5, 5.4.1).

The requirement to involve relatives when a resident lacked capacity was recognised by staff as the example below indicates.

Abeo (registered nurse) *We involve the residents, should know, and then if the resident is not really capable to take the decision we involve the family.*

Staff told me that relatives were generally involved in care planning as this was the policy in the Home. As this example demonstrates, this appeared to be a blanket policy which did not take in to account the capacity of the resident or who they would have liked to involve in any plans for their care.

Ethel (registered nurse) *When we are doing the care plans, according to the policy of the home, we have to include the relatives, so we would tell the relative that maybe if he want to come, “we are going to do your mum’s care plan and if you would like to be there...” Sometimes he says “Oh no, you can do it for her” or if not, also we can ask the social worker or that person’s social worker.*

Relatives, in interviews and informal conversations did not always think they had been involved in care planning. It is possible they were involved but the discussions about care were informal and not recognised by relatives as care planning as the example below suggests.

Julia *when your mum was first admitted did you make a care plan, did the staff make a care plan, were you consulted, were you asked your mums preferences and things like that?*

Derek *No, I can’t recall anything like that happening*

Staff also identified the benefit of involving relatives when a resident was reluctant to receive care. This was seen as particularly important where a relative was requesting care, in this example a hair wash, which the resident was reluctant to receive.

Anna (care worker) *the daughter needs to come and stay around and like encourage OK. You can ask her. Yeh, mum today you’re going to have your hair washed because this and that, you might see that the hair needs washing but then the resident doesn’t need the hair to be washed but if you involve relative then they, the resident, will listen to the relative more than, than you.*

The involvement here appeared to have two purposes, to help deliver care to the resident but also to show the relative that it could be difficult to deliver the care, as staff sometimes felt that relatives did not understand the difficulties they faced.

Some relatives mentioned activities as an unmet need. In this example Christina noted that her husband had little to do.

Christina...the thing that's missing but how do you apply it? Stimulation. I think that is the worst thing because there's only one lady I've seen do anything in here...there's one lady who knits,

Christina put this down to a shortage of staff but was unable to suggest what type of activity David could be involved in.

6.5.1 Facilitators and barriers to relatives' involvement

6.5.1.1 Assertiveness

As with residents (see chapter 5, 5.4.1), there was a marked difference between relatives as to how assertive they were in relation to their involvement in the resident's care and treatment.

Heather had been visiting Iris about twice a week for the two months she had been a resident. However, she had had no discussions about Iris's care or treatment with staff. Iris had dementia and although she could express herself about everyday decisions she lacked capacity to make decisions with more major consequences. Although a future meeting had been arranged, Heather had not proactively arranged to see staff to discuss Iris's care although she had mentioned that she needed more information.

On the other hand some relatives appeared more assertive as indicated in this example by Carol.

Carol I had to stamp my feet a bit to make sure he was showered three times a week, I did have to sort of say look, I want it in the care plan, I want to find out when he was last showered and I want it written down,

The two least assertive relatives, Christina and Heather, were the only two relatives from the same age group as the residents, the other relatives were all of a younger generation. Christina told me that friends said she should be more assertive and demand better care but she said that had never been her nature.

Christina So far I don't seem to have made any impact, if you know what I mean. But I've always been like that. I've never been a sort of person that sort of would say you've got to do this,

It appeared that those who were assertive had more input into residents' care. In this example Carol was asked whether she considered that she had been involved enough by staff in the home regarding her uncle's care.

***Carol** Yes, yes, I think perhaps initially not but erm but I think it's up to relatives you know, people who are responsible for the elderly, to, to actually make sure that you are there.*

The assertiveness of relatives made a difference to their level of involvement in the Home and their satisfaction with that involvement.

6.5.1.2 Expectations

Relatives' expectations also had an impact on their involvement in decision making and what they asked for. Some relatives talked of not getting the information they would have liked from staff, but felt they could not expect too much, an example is given below.

***Christina**...there's a limit to what you can expect people to do isn't there? If he was a private patient and you were paying for everything, well it's a different story all together isn't it?*

Half of David's fees were paid by the Local Authority while David and Christina met the remainder. Because of this Local Authority support Christina did not consider him to be a 'private patient' and this had reduced her expectations of both the quality of care and her influence over it.

As was suggested by residents, some relatives also felt that there was little that could be done to improve care or the speed with which staff responded because the staff were so busy as shown in this quote.

***Christina** I can't honestly see you can do an awful lot about it in here can you? Because they are so limited in staff and they, last night before I went home everybody wanted, one wanted to go to the toilet, the other wanted to go to bed, the poor soul I mean she didn't know which way to turn,*

This perception of a shortage of staff had led to acceptance of what she considered to be less than optimal care. Her low expectations were evident again here.

***Christina** I must admit the first few weeks the staff were absolutely lovely, you know, but once, one or two don't seem to care too much, but when you think of the job, you can understand it can't you? It's not a pleasant job is it? But I think from the way*

some of them treat, you know some of the patients, I mean there's one lady down there, she gets her tea and she just pours it over the carpet, things like that. and you tell 'em off but it doesn't sink in, they don't know, when you've got that to put up with.

Christina had accepted and apparently justified the uncaring attitude of some staff by accepting that their job was difficult and the behaviour of some residents was hard to manage. However, she acknowledged that despite this most staff showed a caring attitude.

Relatives' expectations have been the focus so far in this section, but with financial affairs it was often the expectation of the resident and sometimes the staff that most affected relative involvement. Relatives faced a number of issues around residents' financial affairs. Although two interviewed relatives held a Lasting Power of Attorney for property and finance there were a number of residents who lacked capacity to make decisions about their financial affairs but were still signing cheques etc. at the request of relatives. One relative was applying to the Court of Protection to become a deputy but the process had been going on for 6 months. During that time the relative was managing the resident's finances as best she could which was an onerous task for her. This had delayed the sale of the resident's house, the proceeds were needed to fund care. One relative who had been the only family member who had been involved with arranging her mother's care and finance, although she had three siblings. She felt burdened at the prospect of going to the Court of Protection and of taking on the role of Deputy while feeling that her siblings were criticising her best efforts. Finances appeared to be the issue where relatives most commonly felt burdened but obliged to be involved as it was expected of them and they could see no alternative. Staff did not mention this issue during the study and no support for relatives in this situation was witnessed.

The example below demonstrated the distress experienced by a relative at the time of a residents' admission.

Jeanna I felt totally unsupported...not only was it traumatic for her with being poorly as well but it was traumatic for me I can remember being very upset by her not being able to go home. I wanted her to go home I didn't want her to be here, I didn't like the colour of the chairs, I didn't like the colour of the carpet all kinds of odd little things like that which of course she was oblivious to by then but they were upsetting me.

In this case Jeanna felt unsupported and staff did not appear to recognise the issue.

6.5.1.3 Staff Communication

Communication between staff and relatives was challenged in a number of ways. Some relatives expressed the difficulty of knowing who they needed to ask to obtain information as demonstrated in this example.

Julia ...would you like to be given more information about Ruth and have a bit more input into decision making?

Jane Yes I would really, it's not just about the care, it's just general information, they don't seem to have a book or anything in writing and you just sort of find out things as you go along, you just find out by asking, but you've got to pin someone down to ask them, to know who they are to ask,

From this and other interviews, it seemed that many relatives felt that the communication was sometimes less than optimal and those who were less assertive were left with little input into their relative's care. Staff did not recognise this as a problem.

6.5.1.4 Relative reluctant to be involved

Although many relatives sought more involvement than they had, a significant minority showed a reluctance to get involved. An example was Molly who talked about the difficulty of making decisions for another person when they had not previously expressed their wishes. Thus she concluded, that staff were just as able to make decisions about what was in Jeanna's best interests as she was.

Molly...if my mother had written down specifically that she wanted this, this and this to happen then I would be attempting to ensure it did happen on her behalf now, but as she hasn't I will leave those type of decisions to the nursing staff here.

I interpreted from Molly's comments that she felt burdened by the idea of making decisions and this was exacerbated by the lack of her siblings' involvement. She would have felt that it was her duty to be involved more if her mother had made her wishes clear while still able to do so.

6.5.2 Relatives' rationale for involvement in decision making

Relatives provided a variety of rationales and reasons for their involvement in decisions. There was diversity in the relationships between residents and their relatives. Various ties existed in these dyads. It was often duty which triggered involvement, which came from many sources. Sometimes it was burdensome but accepted through duty and/or affection. As in this example there could be mixed reasons.

Christina He's always been such a good husband,

Family ties were seen as very important. Duty seemed to be based on reciprocity but also in that it was the way it was as this example implies.

Jane she was my mum's sister and we're very, we haven't got any other family and we're just used to looking after each other,

An example of ties of affection is demonstrated here. When talking about when Victor was very ill and had major surgery Carol became quite emotional and explained what she had told the surgeon.

Carol...he's a well loved uncle...he deserved the best chance.

Although affection for Victor appeared to be Carol's main driver in her engagement with his care, she had also said that she considered all relatives to be duty bound to get involved in ensuring their relatives received optimal care.

A common theme amongst relatives was one of guilt, particularly at the time of the resident's admission. A quote from Molly in 6.5.1.2 above indicates how Molly felt guilty at seeing her mother being 'put' into a care home.

Limits to duty were also sometimes identified by relatives as in this example. Jane had previously cared for her mother at home.

Jane And erm, really from the beginning she'd really like to come and live with me but I can't do it 24 hours a day and, I cared for my Mum as well for a number of years and I can't do it for her but she found that hard at first,

This had obviously been difficult for Jane who, although she could justify to herself that she could not do everything, she still felt guilty that she was not able to care for Ruth at home.

Patricia was an employee and a friend of Queenie's. She had no family ties or duty thus her decision to visit regularly was based on friendship. She did seem to be frustrated that she was not able to influence Queenie's care. She had got involved with getting Queenie a better room. Queenie did not have any relatives but she did have a number of close friends who were involved in her care, one of whom held a Lasting Power of Attorney.

Heather was retired and had taken on the role of Iris's most frequent visitor and liaised with the Home. She said that she would share decision making with other family

members. Heather had taken on the main responsibility for Iris as she believed that a family member needed to be involved and it would have been difficult for any of her children to take on the role due to their other commitments. Consequently, Heather felt a sense of duty to her late husband, Iris's brother, her children (ensuring they were not burdened) and to Iris who she was close to. She was not a blood relative but Heather talked of the importance of family in the past. So although Heather was talking of their youth when she did not know Iris, the importance of family may have been another call to duty.

6.5.3 The authority and underpinning values for relatives' decision making

Relatives were generally acting as advisor and facilitator for residents rather than as decision makers. Some held Lasting Power of Attorney which gave them legal authority to decide either on issues of health and welfare and/or property and finance. Only those with Lasting Power of Attorney or a Court Appointed Deputy has a legal right to decide on another adult's behalf (MCA 2005). However, in the case of the relatives interviewed, even those holding Lasting Power of Attorney were first asking residents to make decisions and then enacting them on their behalf. By sharing decision making with the resident they were leaving the authority and responsibility with them. All residents interviewed had considered who should act as a proxy if they were unable to decide for themselves, so this gave relatives moral authority to decide, even if not legal authority. Most relatives were keen to be involved in medical decisions, although sometimes these were made for residents who lacked capacity by the staff without consultation (see 6.2.2).

There was also an expectation by some residents that their relatives would become involved with decision making and assisting residents to enact their decisions, making them feel obliged to act, as in the example below.

Victor *She just put me into the home here. I asked her, I wanted to come and she makes the decisions after that.*

Julia *Yes, she helps you.*

Victor *She helps me.*

Julia *With all the practical stuff really.*

Victor *She helps me. Yeh.*

It was again difficult to ascertain any values which underpinned the way decisions were made by relatives for residents when they lacked capacity. I had tried to frame questions that would be understood for example,

Julia *When you have to make a decision for your aunt, how do you decide, what sort of values would underpin that?*

As with staff, this type of question was often answered with an explanation of the procedure of decision making and sometimes an example. Nonetheless, as can be seen below a number of relatives and friends had established that they would decide with the resident's best interests in mind.

Carol *I'd do what I feel is best for him,*

Patricia talked of another frequent visitor of Queenie's and how she would assertively ensure that her best interests are looked after.

Patricia *I'm sure she'd look after Queenie's interests as well. You know she'd start laying the law down if she thought things weren't right, {laughs},*

Heather simply stated what her concerns were when making decisions for Iris.

Heather *My concern is that she's contented and happy. I mean that is the wellbeing, the main thing that someone is content and happy,*

Julia *So the decision you'd be making would be attempting to make sure that Iris's wellbeing and happiness is looked after,*

Heather *And looked after, that's the main thing.*

Many relatives talked of making decisions collaboratively within the family. Commonly they said that they would not take decisions alone but would involve other family members as this example shows.

Heather *It would be a family decision not really one person it would be a family,*

She emphasised that this related to their generation and a different type of upbringing where family was central to their lives and decisions were not individual but more collective in nature.

Heather *I mean things in the past, in another generation to what they are now, and how we were brought up is very different to nowadays isn't it? We were very family minded weren't we?*

Iris *Oh yes,*

Heather *And respected parents and what they said didn't we.*

Julia *Yes there was an element of obedience when you were younger to your parents and so on,*

Iris *Oh yes, yes indeed.*

The need to involve other family members was not only evident in the older generation. Although Carol held Lasting Power of Attorney she talked of the importance of family support for her and Victor.

Carol I would contact his brother and sister and ask them how they felt and talk to my own sisters, I've got a lawyer and a doctor so that's helpful, I talk to them about what I should do legally and emotionally. I have my family that support me and he does too, he will say, don't worry about this, this is fine or I'm happy to be here and he will always say whenever he's gone to hospital I'm happy to be here and you know and I'm OK.

The value of family and collaboration can be extrapolated from this. Family loyalties, duties and affection has already been identified in relatives reasons for their involvement in residents' lives. As well as motivating relatives to be involved, the family appears to be a valued unit which guides the process of decision making if not the outcome.

However, despite the expressed need to involve other people in the family this is not always without its difficulties as the quote below demonstrates.

Una I do find sometimes the problem is that because my siblings see Mum once a week at most, sometimes once a fortnight, sometimes it's once a month depending on what they're doing, because I'm the one who sees her all the time I don't say that I should have the biggest say but I do think that sometimes, that they are blinkered and they do need to listen to what Mum is saying and what I am saying together and sort of take it from there I think they, they don't always know what's going on with Mum and what she, how she feels and what she thinks and how things are affecting her.

Families were not always a coherent unit and this made it difficult for staff who needed to decide which relative's perspective should be given priority if none held Lasting Power of Attorney.

Relatives talked of helping residents to make decisions as well as helping them to enact them. This was often about issues outside the Home, such as their finance and property. Relatives' involvement in decisions about care and treatment was often to persuade them to comply with what was considered the best course of action by the staff and relative. This appeared to be more coercive than collaborative.

From field notes 1st April 15.00 Molly came to visit Jeanna. As they sat together Anna (care worker) approached Molly and said she could not persuade Jeanna to have her hair washed and obviously it was dirty. Molly said "Is that right mum, you won't let the nurses wash your hair?" Jeanna smiled but did not speak. "Let's see

what we can do.” Anna and Molly took Jeanna to the bathroom. I approached a few minutes later and Anna was washing Jeanna’s hair while Molly held her mother’s hands and quietly asked her not to make to fuss.

Derek was also recruited by staff to persuade his mother to take medication that she had refused. She became compliant at her son’s bidding. Although the relatives did not express what values were behind these actions, beneficence appears to be central as both Molly and Eleanor had severe dementia and were given necessary care.

Relatives were asked how they would make medical decisions on behalf of the resident, some said they would do what the doctor advised. An example is given below.

Heather *Medical decisions I think one takes the advice of the medical people. I’m not a medic, I don’t know,*

Thus, as often seen with residents, the relatives were approaching such decisions with the best medical interests in mind rather than a more holistic view of the person they knew.

Other relatives felt the doctor was not necessarily the best person to decide as is demonstrated in this example. Carol talked of how the doctor might see her uncle and his best interests, differently to her. She told the surgeon that she did not consider Victor to be at the stage of palliative care, taking into account what she considered to be a reasonable quality of life.

Carol *Otherwise, no, I’m not sure, I think they would have looked at his birth certificate, looked at his, the amount of intervention he’s had in his life, he’s had three hip surgeries, he’s had prostate cancer, he’s had skin cancer, so they would have looked at that and thought that that was probably the kindest thing to let him go, but I didn’t feel that was right. I felt that he has, and actually he’s come back and he’s, he’s well and he’s interested in life and sees the children...*

She could see that if the doctor looked only at the medical notes without knowing the person they might come to the conclusion that it would be inappropriate for her uncle to have major surgery. This response stood out from both residents and relatives who had said that they considered the doctor as the right person to decide on medical issues as they had the expertise. Although the doctor does have the medical expertise this relative considered her knowledge of her uncle and his life to carry weight in deciding whether a medical intervention was in his best interests.

Relatives did not always consider survival at all costs should be the aim. In this example Carol had also thought about the consequences of surgery.

***Carol** And before I made the decision about the operation I did ask the doctor if he would be left in a permanent sort of vegetative state, and they said no he would either die in the operation or you know he would come through it.*

That survival at all costs was not the aim was important to other relatives as well. In this example Derek talked of the principles that would guide him if he was making medical decisions on behalf of his mother.

***Derek** The thing that underpins all the decisions is whether it's necessary, and should she undergo the treatment, will it be a problem, what are the consequences of just leaving it, but today the doctor said it's not necessary but we will monitor her every few months.*

He was talking of the benefits against the burdens that the treatment would bring. However, he said that although he had not discussed it with her he believed his mother would want to survive but he put in the following proviso,

***Derek** Not survival at all costs, but survival in comfort.*

The quotes above indicate the importance to some relatives of other factors beside the purely physical that they believe should be taken into account before a medical decision was taken.

As the examples above show a number of relatives considered themselves, as close relatives with an intimate knowledge of the resident, to be the appropriate people to decide as they would know what the resident would want, this is evidenced in this quote.

***Christina** I make it by I know what he'd say, well I've got to this age and I don't think and I wouldn't for myself. You know it's, somebody asked me the other day I think it was the doctor, you know, if erm somebody offers you treatment if you had anything wrong would you agree not to have it? I said on that, I'd do it for myself so I'd certainly do it for David if it came to that. I think 86 I don't think it's worth it to keep having these ops, do you?*

However, she had previously said that she had been happy when David was admitted to hospital without her being consulted. It appeared that her beliefs about her husband's treatment had not been canvassed by the staff and that she had not fully thought through what she wanted for her husband.

6.6 Decisions made by the doctor

While not being a part of the organisation as the staff were. GPs were frequent visitors and some knew individual residents well. Their decision making for residents was authorised in a number of ways. Firstly, the resident gave them permission to decide due to the resident's previous experience with them that had earned trust, their medical knowledge or simply due to their perceived power. Secondly the doctor took on decision making on their own authority with or without the involvement of staff as they held a powerful position. Thirdly they could decide for the resident who lacked capacity in their best interests under the auspices of the MCA (2005) some examples are given in the following section.

6.6.1 Residents authorising decisions

A number of residents reported that they considered the doctor's position in decision making in the Home as relevant. In relation to health decisions, some residents thought they were not best placed to decide and that professionals, especially doctors, knew better what was best for them as they held the medical knowledge. It was notable that almost all residents spoken to about medical decisions separated them from other aspects of their lives. There was a division between the purely bodily needs, for which many saw the doctor as the expert, and their own ideas about what they wanted from life. This is demonstrated in this example.

***Victor** I left the decision with the doctor, I knew he knew more about what was wrong with me than I knew. Whatever the doctors said I'd do it.*

Relatives, like residents, sometimes thought that the doctor would be the best person to make medical decisions, bowing to the superior medical knowledge. Although, as has been discussed above (6.5.3), there was evidence that some relatives took a more holistic view of the person.

Not all residents considered doctors automatically worthy of trust without having first demonstrated their trustworthiness. Faith in a doctor's decision was more conditional as the following quote shows.

***Julia** Do you think in medical things, do you think the doctor knows best and you'd do what the doctor suggested?*

***Iris** I don't honestly know, I think it depends on me at the time and the doctor. I don't mean me in, my condition at the time and the doctor I mean if it was one I knew well then err trusted you know and had helped me before that's fine but if it's newly err,*

Julia That you've only just met, you'd find it less easy to be certain that they'd know what's best for you?

Iris Oh very much so, yes,

Here it was suggested that the doctor may be the one to decide but only if he was known to the resident and had proved trustworthy in the past. It appeared that the privileged position of being considered the authority to make medical decisions was not granted automatically but first had to be earned.

6.6.2 Doctors' role in decision making

In some situations the GP took on decision making on their own authority with or without the involvement of staff. In this example Kieran identifies what he considers to be the inappropriate power wielded by doctors in the Home and does not think they should be trusted to decide.

Kieran ...if the doctor has said it that's the end.

Julia Yes, so you think the doctors make a lot of decisions on your behalf,

Kieran They make a lot of decisions.

Julia And you find it quite hard to argue?

Kieran Well you cannot argue, they say the doctor said that so where do you stand?

Karen was unable to make decisions about her medication as she had not been given the information she needed by the doctor or the nurses. She stated that she would have liked more information and if it was explained to her she would have had capacity to decide. The issue of power is also significant in that Karen believes that it is not the "done thing" to ask the doctor about her medication.

Julia has the doctor talked to you about the medication you're on and what it's for,

Karen No they don't, they talk with the nurse, the doctors know best at least they're supposed to,

Julia So would you prefer to know a bit more about what your medication is and why you're taking it,

Karen Ahhhh that's a difficult thing, I could ask them, it's not the done thing really to ask what the medication is for,

Julia But in a way you'd like to know,

Karen Oh really have the opportune that people should be told

Karen perceived the doctor as holding a superior position, although questioned whether he did know best. She had not given the doctor permission to decide on her behalf, but instead believed that it was his role and that she was not in a position to challenge him. The issue of power was not only perceived to exist between Karen and the doctor, but also

with the nurses. Consequently, she had not asked them to explain about her medication either.

Kieran perceived a hierarchy of power whereby the doctors held the ultimate power and the nurses act on their directions. He saw the nurses as supporting the doctor as the decision maker, a situation in which they had little choice due to the doctor's power.

***Kieran** to kind of restate again the doctor's dominance over everything. The doctor's said so and that's it. It's a fait accompli.*

***Julia** And that's the way that the nursing staff work? They do what the doctor says to some extent,*

***Kieran** Yes, yes. Well, to a big extent, totally...if they don't follow the doctor then they're, obviously they're in trouble. So there's a power thing there, really. Yes there's a real power issue there. Well I wouldn't blame the nursing staff, it's the doctor he has such power over everything.*

No relatives reported that they considered doctors were making decisions on behalf of residents inappropriately or without consultation.

Some residents told of a negative perception of doctors and the decisions they made as illustrated below.

***Nelly**...the doctor, when he's come I've asked him to have a look at it {her toe} for me, and he doesn't have a look at it, he says you're on an antibiotic, you don't need to have it looked at. You're on an antibiotic that'll clear it up, but it didn't clear it up. Funny doctor, you ask to see the doctor, you can't see him, he doesn't see you, he doesn't come round to see you. That's what I find so unusual.*

Nelly was of the opinion that the doctor was not behaving as she thought proper and it appears he expressed his decision without any consultation and without an attempt to accommodate the resident's wishes.

As discussed in 6.2.2 and 6.3, doctors were involved where residents lacked capacity. They collaborated with other members of the team and relatives in deciding what was in residents' best interests under the auspices of the MCA. Nonetheless, some decisions were made which may not have been in the residents' best interests at the request of relatives, and such decisions would have had no legal authority (see 6.2.3).

6.7 Summary

This chapter presented the second central phenomenon of the study: others decide for resident. The findings have been presented in the paradigm model suggested by Strauss and Corbin 1998), see Figure 2 below.

Figure 2. Central Phenomenon 2: Others decide for resident

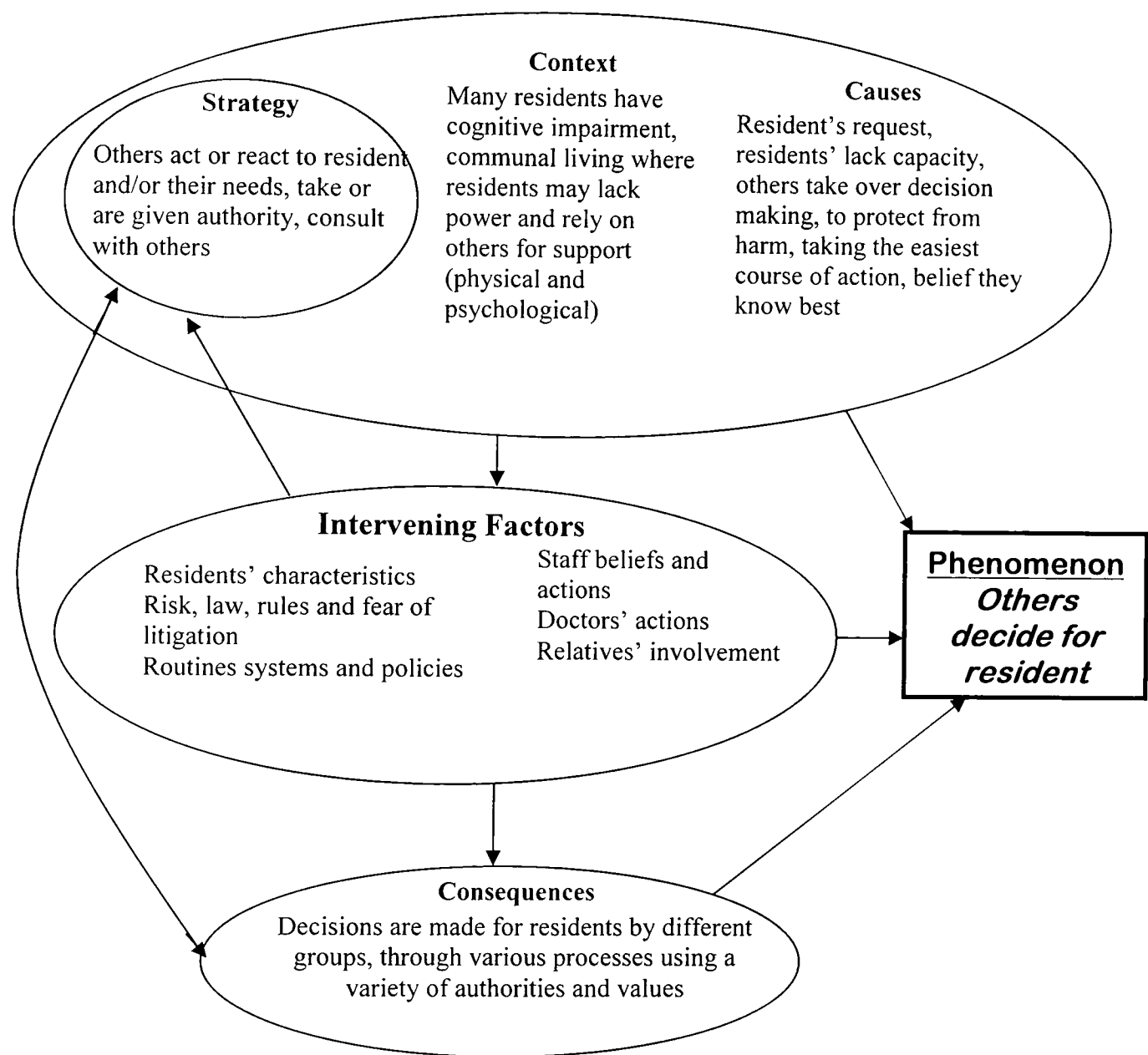


Figure 2 provides a summary of the findings in relation to the phenomenon: others deciding for resident presented in this chapter. The chapter has discussed the decisions made for residents by staff, relatives and doctors. It has considered the decisions each group made, with what authority and/or responsibility and with what underpinning values these decisions were made.

The following chapter provides a discussion of the findings in the light of previous empirical studies and other literature and policy, particularly in regard to autonomy and dignity.

Chapter 7

Discussion

The findings of this study will be interpreted and discussed in relation to the literature. The chapter considers in turn; types of decisions, the two central phenomena, the resident as decision maker and others deciding for resident and how the everyday practice in the care home relates to the discourse on the key values of autonomy and dignity. There follows a discussion on the tension between, on the one hand, desire to respect autonomy with the individual resident at the centre of all decisions and on the other, the need for utility in the running of the care home where the various actors have conflicting needs and care must be provided to many residents in a communal setting. Then, the relevance of the concept of solidarity to the study's findings is considered. Finally, the study's strengths and limitations are addressed.

7.1 Decision types

Decision types relate to research question number one: *What decisions are made in care homes?* The study explored the accounts of decisions and the subsequent analysis suggested that decisions within the care home setting can be categorised into three types; everyday, infrequent and advance decisions. None of the empirical studies presented in the literature review (chapter 2) identified the types of decisions made in care homes. The categorisation of decision types identified in this study is not presented as a hierarchy of importance to participants. The data indicated that each participant group viewed these categories as being of different relative importance. None of the previous studies specifically considered which decisions were most important to the various actors in care homes. Whereas the findings of this study showed that many residents found everyday decisions the most important, the infrequent were important to many but not all residents, regardless of their mental capacity.

Everyday decisions, mostly about care and how residents spent their day, were decisions that could be made by almost all residents. Staff generally accepted that residents were not only able to make these types of decisions but had a right to do so but there were factors that reduced residents ability to make the decisions themselves (see 7.2.3). Such simple

decisions as deciding what to wear, where to spend the day and what to eat were often found to be important for residents. Relatives generally reported leaving most everyday decisions to staff, however they would become involved if they considered their relative was not receiving what they perceived to be acceptable care (see section 7.2.3.7 for information on relative involvement).

The infrequent decisions consisted of medical decisions including prescription of medication and hospital admission, financial decisions and where the resident would live. There were some residents who had capacity to make some or all of these decisions. However the actions of staff and doctors did not always enable residents to make their own decisions particularly where medical decisions were featured and decisions were considered unwise. Relatives often supported residents with financial decisions and their enactment. These issues are discussed in detail in section 7.2.3.

Those studies that focused on advance decisions (Froggatt et al 2009 and Froggatt and Payne 2006) did not discuss the importance of advance decision making to residents, whilst in this study it was found that these issues were rarely thought about by residents and most said that they did not think them important. This was sometimes because they considered the way illness and end of life was managed in the Home matched their wishes, something else not considered in previous studies. The lack of awareness by residents that advance decisions had been made, even where decisions had been recorded in documentation, was another new finding. Exploration of the reasons for this can be mooted, but further investigation is needed of this and ways to ensure residents are aware of any advance decisions they have been deemed as having made and the utility of asking all residents and relatives about advance decisions (see recommendation 7 in chapter 8, 8.9.2).

7.1.1 Advance Decisions

In this study, most residents did not consider advance decisions important. Other studies have considered this issue mainly from the perspective of staff and relatives. Froggatt et al (2009) found that care home managers considered that advance care planning was important for the provision of good end of life care. Jones and Manthorpe (2002) found that while staff and relatives thought it was important to talk of death and dying half of the residents disagreed. There is a discussion of end of life planning and decisions relating to

who would be a proxy decision maker in the event of incapacity in the results, chapter 5. 5.5, 5.5.1 and 5.5.2 chapter 6, 6.3.

Most residents and their relatives considered that a relative was the most appropriate person to make proxy decisions for the resident in the event of loss of mental capacity although few had discussed end of life preferences. Contrary to the belief expressed by relatives and residents that relatives would know what residents wanted, the systematic review of empirical studies designed to assess the accuracy of surrogate decision makers' perception of what their relative would want, Shalowitz, Garrett-Mayer and Wendler (2006) found that the surrogate decision maker was accurate about 68% of the time. So, almost one third of their decisions were not what the resident would have wanted. They also considered the need to assess whether there are advantages for people and their families if relatives are making decisions even if they may not concur with what the patient would have wanted. These recommendations appear appropriate in relation to this study's findings.

Some staff were involved in advance decision making. Most care workers did not consider this to be part of their role, although one interviewee did say that residents sometimes spoke of these things and she passed this on to a registered nurse. There was reluctance amongst several of the registered nurses to talk to residents about end of life when they were still well. Froggatt et al (2009) also noted that staff often lacked the confidence to discuss end of life issues with residents.

However, more senior staff did report that it was policy in the Home to discuss treatment and end of life issues and, where possible, offer residents the opportunity to make advance decisions. The Home subscribed to the Gold Standards Framework (2012) which requires that advance care planning on end of life issues is offered to all residents in a care home. However, in this study residents did not appear to recognise that decisions had been made even when they were documented. Froggatt et al (2009) found that managers reported that it was often difficult to involve residents in discussions due to their cognitive ability even at admission. This was sometimes the case in this study.

As advance care planning can improve end of life care and reduce the incidence of unnecessary treatment and hospitalisation it is an important element of decision making in a care home (National Gold Standards Framework Centre 2010). However, as this study

showed there was a reluctance to discuss these issues amongst many residents and some relatives, thus it would be difficult to universalise the practice (see chapter 8, 8.9.2 for recommendations).

I now turn to the two central phenomena identified in this study, that of the resident as decision maker and others decide for resident.

7.2 Phenomena: Resident as decision maker and others deciding for resident.

The two phenomena were derived through the analytical coding of data and the employment of Strauss and Corbin's (1998) paradigm model (chapter 3, 3.4.4.4). The paradigm models can be found in Figure 1 in chapter 5 and Figure 2 in chapter 6. The causes, context, intervening factors and strategies are considered, together where appropriate, in the light of the wider literature. The consequences are considered in relation to the various elements of paradigm.

Within this section on the phenomena the research questions; *Who makes decisions, with what authority and/or responsibility?* and; *What are the barriers and facilitators for residents to making their own decisions and what factors influence relatives' involvement?* are addressed.

7.2.1 Causes

The findings from all participant groups in this study showed that almost all residents were able to make at least some decisions about their everyday life. A desire by residents to make decisions was evident in many but was not universal. This was similar to findings of Boyle (2004) and Scott, Välimäki, Leino-Kilpi et al (2003). The other studies identified a strong desire by residents to make their own choices and Cook (2008) identified strategies that were used by residents to retain control to give meaning and purpose to their lives and make it more enjoyable. Train et al (2005) and Jones and Manthorpe (2002) also noted a strong desire by residents to make their own choices. The meaning of decisions and choice was discussed in chapter 1, 1.2. As I suggested, choice is the more appropriate term when considering everyday life. The use of the term choice was evident in most empirical studies.

Relatives sometimes believed that the resident was unable to make any decisions on their own behalf. However, most staff considered that all residents were able to express at least some preferences about their care. Staff reported their belief that residents had the right to make decisions about their everyday life. This study found that staff considered that offering choice to residents would increase their wellbeing; this mirrored the findings of many previous studies (Knight, Haslam and Haslam 2010; Clarence-Smith 2009; Dunworth and Kirwan 2009; Froggatt et al 2009, Hughes and Goldie 2009; Froggatt and Payne 2006; Train et al 2005; Jones and Manthorpe 2002). Nevertheless, residents' choices were sometimes overridden by staff's concern that they must deliver appropriate care or that residents were at risk of harm. This is discussed in the following sections.

7.2.2 Context

Contextual issues were the same for both phenomena. The significant factors identified in the analysis were that this was a setting of communal living where residents relied on others for support (physical and psychological) and at times lacked power to assert individual preferences.

Residents in care homes are there precisely because of their need for assistance, physical and/or psychological, as such they are at risk of loss of autonomy and limitations to their choices and, as Agich (2003) suggested, even the benevolent use of power is a threat. At times residents were unable to make decisions and others had to take over. These issues were evident in the findings of this study. The context led to the identification of the intervening factors which are discussed below and which explain these findings.

7.2.3 Intervening Factors

Seven intervening factors were identified and are discussed below.

7.2.3.1 Residents' characteristics

The residents' characteristics affected whether they made decisions on their own behalf. These included their assertiveness or passivity, their expectations and faith in their own abilities, as well as their physical and cognitive ability. Some residents had severe dementia and this meant that they could not make decisions but often, through nonverbal communication, could demonstrate some preferences.

Residents in this study varied in their assertiveness. Those who were more passive had significantly less control over their life and care, although they did not necessarily perceive this. This corresponded with Boyle's (2010) findings that residents did not always take the opportunity to make choices even when it was available to them. However, Cook (2008) found that residents were employing strategies to retain control although others did not always recognise this. The findings of this study were more mixed, drawing attention to the heterogeneity of care home residents. Advance care planning was not common in the Home and, as Froggatt et al (2009) found, not all residents were willing to engage in planning for end of life. The amount of control residents perceived they had also varied over and above the differences in what they were actually seen to have. This can be explained through the theory of locus of control (Rotter 1966). Some residents appeared to show an internal locus of control, believing that what happened to them was under their own control and that they were making all the decisions about their lives for themselves. Those with an external locus of control felt they had little control over what happened to them. According to Gross (2010) this in turn leads to learned helplessness (Seligman 1975). Some of the comments made by residents suggested that they may have experienced learned helplessness, in that they believed that no matter what actions they took they could not control the outcome (Seligman 1975).

Seligman (1975) hypothesised that this uncontrollability leads to deficits in motivation, cognition and emotions. The cognitive element is that it is not solely the lack of control that leads to helplessness but the expectation that outcomes are uncontrollable. Motivation is affected in that responses to a potential outcome become retarded because of the belief that it cannot be changed. The hypothesis then claimed that depressed affect results as uncontrollability is perceived. Abramson, Seligman and Teasdale (1978) identified three important attributions that affect how a person reacts to uncontrollability. These are internal/external, stable/unstable, global/specific. The first of these relates to locus of control (Rotter 1966). Abramson, Seligman and Teasdale (1978) suggested that the lack of control can be attributed to themselves (internal) or a situation where no one would be able to control it (external). If a person perceives the lack of control to be internal their helplessness can also lead to low self esteem. A situation can be perceived as stable, being either long lasting or likely to reoccur, unstable or of short duration or intermittent. The situation in a care home is long term and likely to recur. This stable situation can lead to chronic helplessness and depression. When a situation is seen as specific, it occurs in a narrow range of situations, while global is across a wide range. It was noted in this study

that some residents were quite assertive regarding some decisions but passively accepted other's control over other issues. The idea that this helplessness occurs in some situations but not in others, e.g. was specific, explains some of the inconsistency in some residents' motivation to make various decisions.

From the participants' comments in this study it appeared that those who experienced learned helplessness, generally perceived it as a result of external forces related to living in an institution, an external attribution. It was stable as the routines and experiences in the Home were mostly consistent, although the way staff members worked could vary. It was seen to be specific with some residents who were much more motivated to take control in some circumstances than others where they suggested their attempts would change nothing. The theory of learned helplessness was not discussed in any of the reviewed studies (chapter 2, 2.6).

Residents' expectations varied between individuals whether they experienced learned helplessness or not. In this study expectations appeared to come from residents' perception of long term care, some believing that it should be focused on their individual needs, while others considered that they would have to fit in with what the Home could offer. This applied both to expectations in relation to the care and service they received and the amount of choice and opportunity to make decisions. Predictably, those with lower expectations would accept less than optimal care and services and were less likely to be assertive in asking for choice and making decisions. Among some residents there was an acceptance that they could expect routine and authority as the default of life in a care home. Rather than demanding autonomy, they were accepting heteronomy, the rules laid down by others. Both Hughes and Goldie (2009) and Boyle (2004) also noted that residents were often compliant and did not always challenge either care or services they were dissatisfied with or where staff retained control. Jones and Manthorpe (2002) found that residents accepted that their choices would be reduced due to the constraints of communal living.

Expectations also affected perceptions of how much control residents had of their lives. This appeared to correlate with their life histories. As several of the residents had lived in some sort of institution, experiencing communal living, they assessed their current opportunities to make decisions and choices as plentiful, even expressing gratitude at being given options. Other residents, who had led more independent lives, stated that their

choices about how they should live were not fully considered. Some relatives considered that low expectations could be due to the residents having experienced hardships in their earlier lives, leading them to expect less.

Residents with physical impairments were dependent on others to enact decisions. This dependence meant that those with the least physical abilities had the fewest choices. They may have been able to make decisions but were unable to carry them out. This is separating decisional autonomy from executional autonomy (Collopy 1995), although it may be better to substitute the word capacity for autonomy. Both the decisional and the executional would be needed for a resident to carry out their wishes, support could be offered once a decision was made, enabling the resident to enact their decision.

Some residents with physical ability were restricted by staff in the interest of reducing risk, for example being prevented from going out alone if at risk of falling. Those residents with severe cognitive impairment could not make infrequent or advance decisions but were often able to express choices about everyday life. Staff did not state that they considered residents' mental capacity when deciding whether to honour their decisions. Other issues, particularly perceived risk, were more significant in whether residents were given choice than was their mental capacity. Most staff demonstrated a lack of knowledge of the Mental Capacity Act (MCA) (2005) and consequently its implementation was limited. This is worthy of further investigation.

7.2.3.2 Risk, law, rules and fear of litigation: A right to take risks

Risk of harm was shown to be one of the major reasons cited by staff as to why restrictions were placed on residents' decision making. Avoidance of risk was voiced as a justification for restricting the options of residents whether or not they had capacity. This reflected the findings of Dunworth and Kirwan (2009); Hughes and Goldie (2009); Train et al (2005) and Boyle (2004) who all identified staff in care homes balancing residents' right to decide with the need to ensure safety. In contravention of the Care Quality Commission Essential Standards (2012a), fear of risk sometimes led to residents' rights being compromised.

Risk of an adverse event is, according to Zinn (2008 p5) "probability_{event} X damage_{event}".

Nevertheless, risk is a part of everyday life and as Zinn (2008) suggested it can also be a need. In this study, risk was generally perceived as entirely negative by staff and often by relatives and something from which residents needed to be protected.

St Bernadette's Service Users' Guide stated that care will be delivered, "Ensuring that assessments are made which balance risks and needs. Promoting a level of responsible risk-taking in daily living activity." Although this was the aim of the Home, positive risk-taking was little practiced by staff.

This situation has been recognised by writers on the topic of risk in health and social care. While arguing that the taking of risks can be a positive aspect in people's lives, Titterton (2004) believed that there were numerous pressures on staff to put the safety of those in their care first. He identified a number of problems with a 'safety first' approach,

- It ignores the other needs of vulnerable people
- It denies them the right to choice and self-determination
- It leads to a loss of a sense of self-esteem and respect
- It can lead to a form of institutionalisation with the loss of individuality, volition and a loss of independence
- At its worse, it can lead to the abuse of vulnerable people.

(Titterton 2004 p15)

If risk is considered a need and something that makes life more interesting, residents are potentially being harmed by the risk averse attitudes of staff, so why this attitude prevails is worthy of discussion.

Although Weaver (2011) placed emphasis on the importance of avoiding risk and more especially harm, she acknowledged the need to balance this against the rights of those being cared for to make decisions about their own lives and to take some risks. Weaver (2011) recognised the potential conflict that exists between the duty to ensure a person's safety while respecting their autonomy and allowing them to make their own choices and decisions. Titterton (2005) expressed the belief that a risk taking approach has been a recent development in health and social care amongst those working with vulnerable people. He saw this as positive in that he considered it is an essential component in improving quality of life. This approach was rarely evident in this study.

Zinn (2008) pointed out that risk assessment is often carried out intuitively using pre-rational techniques. As was found in this study, risk assessment was not always a formal process but often consisted of staff making on the spot decisions about whether they considered a risk acceptable. Lesser (2007) expressed the view that the presumption should be that compulsion to avoid risk should be avoided and if used, required justification. He suggested that this is because autonomy is valuable in itself (see 7.3.1.1). Lesser (2007) argued that only if someone has been assessed as lacking competence can compulsion be exercised, and then only if they are a danger to themselves or others.

Titterton (2005) found in his extensive experience in training social workers and other professionals that unimaginative and defensive practice was the norm as there was little knowledge of the law and an unfounded fear of litigation. This type of practice was often in evidence in this study, with the lack of consideration of residents' capacity, a finding in this study not identified in other studies. However, there was evidence of some thoughtful reflective practice among some registered nurses who sought ways of protecting residents from harm through negotiation rather than overriding the wishes of competent residents.

Positive risk taking is about allowing people to make their own decisions even if there is an associated risk. Care staff can act to manage or minimise these risks (UNISON 2011). Carson and Bain (2008 p25) suggested that "risks are justifiable not just excusable". In this study a number of issues around risk were raised, see chapter 6, 6.2. UNISON (2011) suggested stringent conditions that should be met if a risk should materialise into harm. They suggested that practitioners should be able to demonstrate that a thorough assessment was carried out, "all reasonable steps had been taken to avoid harm, decisions had been recorded and procedures carefully followed." (UNISON 2011 p21). Understandably, staff were concerned that they could be blamed if harm came to a resident. This led to staff acting in defensive ways for example; monitoring residents covertly, preventing them deviating from their diabetic diet, having unnecessary capacity assessments and often keeping individual's personal spending money locked away in the Home safe.

It was found in this study that risk assessment was carried out to avoid subjecting residents to unnecessary harm and implement strategies to minimise the risk of harm. However, there was evidence of risk aversion which appeared to relate to the risk of a member of staff being blamed for a negative outcome, rather than purely a risk of harm to residents.

This was notably evident in the case of hospitalisation of a resident who became unwell when no decision to the contrary had been reached.

A nurse, a ward manager, quoted by Titterton (2005) said “total safety” can only exist in an environment of “total control”. This was evident in this study. Practices that contributed to this were, the covert observation of residents considered to be at risk of harm, the control of food, the use of a single GP’s practice and bringing in services such as hairdressers and clothes sales and even the religious services to avoid residents going out where they could be at greater risk. Hughes and Goldie (2009) found, retaining control, in their study in relation to the administration of medication, led to ease of maintaining adherence and the best medical outcome, but they also recognised that this deprived residents of autonomy and control. This type of control mirrors the ideas put forward by Goffman (1961) with regard to the “total institution”.

The concept of a total institution, according to Goffman (1961), consists of a place where all daily activities, work, sleep and play all occur in the same place, with the same group of people, governed by the same authority. The routine activities of the day are scheduled for all to “fulfil the official aims of the institution” (Goffman 1961 p6). This in many ways describes a care home. As the findings of this study showed there were unquestioned routines in place, the main meal at lunch time for example. Activities were scheduled for groups rather than individuals and as Goffman (1961) contended, this made supervision easier for a small number of staff. The separation from the outside world of “inmates” is also seen as a characteristic of the total institution. In the Home, few residents went outside as the services were brought to them. The staff decided who needed to see the doctor and sometimes, as the findings showed, the doctors and staff did not share all the information with residents. As described in the concept of the total institution, “inmates” or residents often had little purpose or meaningful activity. Much of the mortification of “inmates” as they entered institutions can be thought of as things of the past, which Goffman (1961) described as acts of deliberate humiliation e.g. removal of own clothing, naked physical inspection and de-lousing on entry, irrespective of need. However, other aspects identified by Goffman (1961) can still be detected. Entry to a care home leads to loss of role, a number of relatives noted the change in residents and although this was sometimes due to loss of physical or cognitive ability, the change to their position in society was also often relevant. Cook (2008) found that residents had to find new ways to construct their lives in care homes as previous roles outside the home were lost. Knight,

Haslam and Haslam (2010) found that residents taking on the role of decision makers about décor in the home resulted in benefits for their health and well being, the loss of roles outside the home being substituted by new roles and status. Decisions of this kind were made by the management in the Home without input from residents and their relatives.

Goffman (1961) argued that total institutions can take away self determination, autonomy and freedom of action and this can leave the person feeling infantilised. This is a high price to pay for reducing the risk of physical harm, the trade off being potential psychosocial harm. A total institution, as described by Goffman (1961), divided the staff who held the power and the “inmates” who had to comply with the regulations. In this study there was still a strong divide between staff and residents. The staff perceived their role as to provide care and treatment and to keep residents safe while residents were the recipients of care. The staff viewed their duty of care through a lens of their legal obligations to ensure resident safety.

Duty of care, when spoken of by staff, was used as their obligation to provide good safe care. It is a legal term and is defined in the Legal Dictionary (2005) as “a requirement that a person act toward others and the public with watchfulness, attention, caution and prudence that a reasonable person in the circumstances would” and if this level of care is not delivered and as a result harm materialises, a person or organisation is deemed negligent in law.

If a person has capacity and wants to take risks, it is unlikely that a member of the care home staff has a legal duty to restrict their actions. It is more likely that preventing a person with capacity from doing as they wish would break other laws, e.g. Human Rights Act (1998), MCA (2005) Deprivation of Liberty Safeguards. The text books that guide nurses on the law are quiet on the issue of whether it is a breach of their duty of care to omit to take action to prevent a harm (such as a fall) when the individual wishes to take a risk (Buka 2008; Giffiths 2008; Tingle and Cribb 2007). An omission to act to prevent the person from taking a risk could be said to be the cause of an incident. The obligation in light of legal definitions of negligence would be, once risk was assessed, to inform the resident that their behaviour had risks of harm and advise them against the action and offer safer alternatives, e.g. leaving the care home with an escort. Once this was done and

documented if a person still insisted on the risky behaviour, there would be no breach of duty of care (see UNISON 2011 above).

The MCA (2005) also codified the offence of wilful neglect. This offence applies when a duty of care is owed, such as with staff in a care home, and only to those who lack capacity. Ill treatment and wilful neglect are not defined in the Act but the Crown Prosecution Service (2009) advised that these terms should be given their ordinary meaning. It is however unlikely, that care home staff would find themselves on the wrong side of the law for practicing responsible risk taking. Ridouts (2010) noted that failure to carry out appropriate risk assessments or allowing a person to harm themselves or another could leave staff culpable. However, harm can be psychological and emotional as well as physical. I argue that allowing more freedom of action could result in greater psychological, social and emotional well-being making the risk of physical harm an acceptable trade off.

The staff in the Home appeared to be largely unaware of relevant law. The MCA (2005) was only mentioned by two members of staff in interviews, both registered nurses, and one named it incorrectly as the “Mental Act”, then it was only spoken of briefly without evidence of deep understanding. The Human Rights Act (1997) was only mentioned by one registered nurse and there was no reference by any other staff members to any other laws.

Fear of blame went wider than fear of the law. Fear that relatives would blame them or that they could be pilloried by the press was also present in the discourse of staff. Khatri, Brown and Hicks (2009 p320) reported a “rampant blame culture in health care” characterised by unwillingness to take risks or admit to mistakes for fear of negative consequences. They wrote of organisational blame culture but this can also include relatives and more widely the press, the public, governmental organisations and the law. Regardless of the reality, if staff perceived that they could be blamed their accounts suggested that they acted defensively, avoiding risk.

Fear of risk resulting in defensive practice is the major reason staff restricted residents’ decision making. The literature on the topic suggests that this is a widespread problem. McCormack and McCance (2010 p1) purported that providing care within the principles of person centred care “treating people as individuals; respecting their rights as a person;

building mutual trust and understanding, and developing therapeutic relationships”, is irrefutably an inherent good. Kitwood (1997) suggested that maintaining personhood is the central task of dementia care once physical needs are met. He saw this as enabling: choice, use of abilities, expression of feelings and living in the context of relationships (Kitwood 1997 p60). This type of care is stifled in a risk averse environment. The implications for practice are discussed in the final chapter (8.9.4).

7.2.3.3 Routines systems and policy

Routines are important to many people living in care homes and can be particularly so to people with dementia. Öhlander (2009) argued, routines are part of good care for people with dementia. McCurry and Ancoli-Israel (2003) pointed out that any change in daily routine can increase confusion and lead to sleep problems. Routines can help those with dementia to remain orientated to time and place. However, routine is not the same as residents of care homes having to fit in with what is convenient to the staff and management of the home. Glendenning (1999 p174) argued that the commonest abuse in care homes is institutional abuse where “the environment, practices and rules...become abusive in themselves”. As Fazio (2008) believed, care could be tailored to the needs of each resident and this would avoid this potential for abuse. Care planned and delivered, with the resident for the resident, is the basis of person-centred care (Kitwood 1997).

Inevitably for an organisation such as a care home to function there are routines, systems and policies in place. Individual routines, set up to suit each resident is more difficult than an all encompassing schedule for all residents, for example, Hughes and Goldie (2009) noted that it was administratively difficult to run two systems of drug administration concurrently. In this study two residents did self administer their medication which the staff considered important for their independence. Tailoring routines to the individual within the constraints of the available staff allocated to each shift was problematic. Consequently, there were group activities which suited some residents but not others. routine bath days, regular doctors’ visits at specific times and fixed meal times.

The CQC (2012a) essential standards for quality and safety include:

- involving service users in discussions about their own care and treatment and to enable them to influence the delivery of services;
- gaining consent before care or treatment;
- service users rights must be supported;

- individual dietary needs must be met;
- there should be enough staff to keep people safe and care for their health and welfare needs.

The ethos of the Home, laid down in the Service Users' Guide, widened these standards (see chapter 4, 4.2). The Guide suggested that these high standards are the way that services would be delivered rather than being purely aspirational. However, the research showed that these claims were not always delivered. Acceptance of reduced choice was evident among many residents in this study. They saw busy staff, other residents with high needs and usually accepted the routines in place (see chapter 5, section 5.4.4.2). Activities were arranged for groups and did not suit everyone, there was little activity for individuals who did not want to be involved in the group, something noted by Train et al (2005) who recommended the need for more tailored activities. Admission to hospital was usually decided by staff. There was also the difficulty of a community of people both with dementia and others who were cognitively able. Some people who were cognitively able did not feel comfortable mixing with people with dementia and chose to remain in their rooms alone and isolated. The resident who spoke of this issue considered that there was nothing that could be done about this when living in a communal environment. This finding echoes that reported by Jones and Manthorpe (2002).

The tension between the need to care for the individual and the good of the organisation as a whole led to staff, and sometimes relatives, having their beliefs and values challenged as they came to terms with dealing with these competing needs. Some of these findings indicated that the care fell below the Home's own Service User Guide standards and in some cases it is questionable whether they met the CQC's essential standards. There was, at times, little consultation with residents about their care and treatment and residents and relatives had little influence over the way services were delivered. This sounds like a very negative view of the care delivered at the Home but the reality was that a generally caring group of staff were delivering care to the residents as best they could within the existing limits and constraints. Nearly all residents were satisfied with most elements of the care they received, accepting limitations as part of communal living. There is a need for new and novel ways for staff to gain feedback to assist them in developing their practice to deliver care more in line with the Home's mission as expressed in the Service Users' Guide and, crucially, the CQC standards.

7.2.3.4 Staff: their beliefs, actions, strategies and communication

The way staff interacted with residents and the strategies they adopted had significant effects on whether residents were able to make their own decisions. Most staff considered it possible to ascertain residents' preferences even if they had severe dementia or had other communication difficulties. However, studies that included different groups of participants, residents, staff and relatives noted differences in perception of information and choice offered and what was considered important (Train et al 2005; Scott, Välimäki, Leino-Kilpi et al 2003; Jones and Manthope 2002) and evidence of the quality of communication between these groups varied between studies. This study identified staff with the ambition to offer choices to residents in many areas of their lives but, for the reasons discussed here, not always achieving this.

As already intimated, communication was key to ascertaining residents' preferences. In the Home, many of the staff did not have English as their first language and some had strong accents. This made some communication difficult and the lack of cultural commonality added to these problems. Residents with dementia were sometimes further confused by the difficulty of understanding staff and making themselves understood. Some residents without cognitive impairment considered staff unable to communicate well in English, regardless of the actual standard of staff's spoken English, this left them feeling isolated.

As Larsen et al (2005) identify there has been a significant inflow of nurses who trained overseas into the UK, many from developing countries. Thus the situation in this study of a largely Caucasian group of residents being cared for by nurses, care workers and managers as well as managers who were not Caucasian, were largely from outside Europe and were not native English speakers, was not unusual. The need for nurses to have cultural competence to provide culturally appropriate care to a diverse mix of people is evident in the global move towards competency based training (Hixon 2003). Articles in professional nursing journals provide advice to nurses on how to respond to the cultural need of those in their care (Beavan 2006, Howard 2004).

However, there is relatively little discussion of the large number of overseas nurses and carers and issues around care staff language, accents and cultural differences to the indigenous English speaking population who still make up majority of care home residents

(Age UK (2012) states that only 8% of people over 60 in England are from black and ethnic minority groups). Cowan and Norman (2006) identify that the UK could learn from the USA on the orientation and enculturation of migrant nurses. Bola et al (2003) identified some of the problems of foreign educated nurses entering the USA health care system. Specifically they noted that communication barriers could frustrate nurses their colleagues and patients. Verbal and written communication could be problematic but also non-verbal communication also provided challenges with these nurses sometimes being seen as “inattentive, subservient or disrespectful” (Bola et al 2003 p40) . Bola (2003) states that Russian nurses had limited training on many issues that would be central in the USA including, death and dying, patient education psychosocial support, patient advocacy and decision making. Although this was about Russian nurses in the USA, it is easy to see how nursing education reflects the culture and values of the country in which it is embedded and how this varies from one country to another. How culture and language of staff affect resident autonomy and choice and decision making more generally is complex and it was not possible to separate these from other issues in this study to reach firm findings.

Some residents reported that staff “don’t speak English” (see chapter 5, 5.4.4.3). Although staff often had accents and did not have English as their first language, all spoke English at least adequately. Whether this revealed issues of prejudice on the part of the residents or whether prejudice was evident from the care staff to residents or between staff groups from different countries requires further investigation.

As the UK empirical literature on choice and decision making did not address the prevalence of staff from overseas with a language other than English as their native language, there is a need for further exploration of whether more choice and control is experienced by residents in settings where there is a higher ratio of staff with English as their first language. Further, care homes where the management has addressed increasing staff knowledge of British culture and/or reducing problems with accents require investigation.

On a positive note, some empirical studies, specifically Wheeler and Oyeboode (2010) found staff using imaginative strategies to take opportunities to turn physical care giving into individual activities. This could fill the void for residents who did not want to take part in group activities and might provide some activities of the resident’s choosing. No

one in this study talked in this way and activities were seen as separate from delivery of physical care. Staff appeared to believe that the group activities were sufficient but some residents would have valued more individually directed activities. this finding was in line with other studies, (Train et al 2005 and Tester et al 2004). showing limited understanding between staff and residents. The Northern Ireland Human Rights Commission (2012) go as far as to suggest that leaving people without meaningful activity or interactions could breach their Human Rights, Article 8 or even 3 (Human Rights Act 1998).

The CQC (2012b) noted that, although most homes had a policy on consent, issues such as nonverbal communication was often absent. In the Home some staff showed innovative ways of establishing residents' preferences about everyday life and care. However, they did not always recognise residents' attempts to express their wishes, reflecting Cook's (2008) findings, and relatives were rarely consulted to help with this. Wheeler and Oyeboode (2010) found that although staff recognised that relatives were an invaluable source of information about residents, there were wide discrepancies between homes in the level of relatives' involvement.

Alongside some good practice, there was evidence of staff accepting compliance as choice. In this study residents were not always informed about their medication or conditions (similar to findings by Hughes and Goldie 2009) and not offering them the opportunity to make choices. Further, similar to the findings of Wheeler and Oyeboode (2010), some staff and relatives used bribery with sweets to obtain compliance. This was done with good intentions but was paternalistic and somewhat infantilising in practice.

Power, defined by Weber (1978 p53) as "one actor within a social relationship will be in a position to carry out his own will despite resistance" is an important concept in relation to decision making in a care home. The empirical studies often referred to the empowerment or disempowerment of residents (Knight, Haslam and Haslam 2010; Wheeler and Oyeboode 2010; Hughes and Goldie 2009; Scott, Välimäki, Leino-Kilpi et al 2003). Most frequently empowerment/disempowerment is considered in relation to residents. However, in this study many care workers believed that any sort of decision making was not part of their role. There was a hierarchical staffing structure in the Home and care workers considered themselves powerless so rarely spoke out to influence care. Similarly, Wheeler and Oyeboode (2010) considered the powerless role of care workers who often were not involved in decision making.

In this study registered nurses mentioned the need to involve the multidisciplinary team in deciding what was in the best interests of residents in relation to healthcare issues as is required by the MCA (2005). Similarly, Froggatt (2009) found staff involving relatives along with residents in advance care planning and the multidisciplinary team in implementing the plans.

Some staff were more perceptive and open to residents' expression of their wishes than others. There was evidence of some staff making considerable effort to establish what residents wanted, resulting in residents being able to make decisions and to execute them with appropriate assistance. This was not always the case and the communication skills, attitude of staff and the strategies they employed had a significant impact on residents' ability to make decisions on their own behalf.

7.2.3.5 Staff numbers

As discussed in 7.2.3.3 above, staff numbers in this study were not always high enough to allow for the CQC (2012a) essential standards to provide, not just a safe environment and care for residents' health needs but also for their welfare needs. However, the care levels were considered satisfactory in the CQC inspections. From my personal experience of care homes (see chapter 1,1.4), the staffing levels were as high as in other similar homes. However, this level of staffing made it difficult to achieve welfare standards that provide more than good, safe basic care. Limited staff numbers restricted the flexibility in care activities, kept residents waiting for personal care and individual activities were difficult to provide. Restrictions on residents' choices due to staff numbers has been found in other empirical work, (Boyle 2010; Hughes and Goldie 2009). Staff in this study reported that there were sufficient numbers, suggesting that the goal was to provide safe physical care and other types of welfare were desirable rather than essential. Residents were generally understanding of staff's need to care for all the Home's residents. Nevertheless, many did report that they were kept waiting for care. Several residents did not always ask for care which they would like to receive as they perceived the staff to be too busy. This led to some residents not being bathed as frequently as they would have liked for example.

In this study, due to staffing levels, staff had to find ways to deal with the dissonance between their desire to provide best care and the shortage of time which impinged on this. Short cuts were sometimes justified by staff where compliance was taken as consent and

decisions were made with little consultation to avoid this difficult and time consuming process. However, staff did not acknowledge that there was any problem with staffing levels. This could have been an attempt, possibly subconscious, to reconcile the care they could give with the ideal. This may well be a coping strategy without which staff would burn out, however examination of how these strategies affect staff practice and their welfare needs further investigation.

The Northern Ireland Human Rights Commission (2012 p71) suggested that low staffing level could be viewed as “an accepted indignity”. The report declared that staffing levels are rarely set higher than those needed to provide the “minimum essential levels of care.” (Northern Ireland Human Rights Commission (2012 p71). They suggested that this leads to staff hurrying personal care and having little time for meaningful interactions with residents. The Royal College of Nurses (RCN) (2012a) reported “persistent challenges to providing quality care”, stating that staffing levels in many care homes were inadequate to guarantee a safe environment. Recommendations for policy are presented in chapter 8, section 8.9.1.

7.2.3.6 Doctors' actions

All residents were registered with the same GP practice, thus the doctors were involved in decisions about the care and treatment of residents. Registered nurses saw this as collaborative and supportive, often talking of decisions being made by the team. They considered it necessary to involve GPs in decisions as neither staff nor relatives could make treatment decisions alone. This is in compliance with the MCA (2005) which states that all those involved in caring for a person and interested in their welfare should be involved in deciding what is in their best interests.

This study identified at least a perception by some residents of the powerful position of the GPs in decisions (see chapter 6, 6.6.2). Passive compliance with treatment was common and information provision often limited. Hughes and Goldie (2009) also found that residents accepted control of their medication by GPs and staff without question and although some residents were well informed others were not. It was not discussed in their research whether residents were offered information about their medication.

This study found examples of decisions to resuscitate residents at their own request even when this was considered to be clinically inappropriate. There was also an example of

similar decisions made about a resident who lacked capacity, where it was demanded by a relative. This was not identified in any of the reviewed studies (chapter 2). However, studies on the efficacy and application of medical treatment were excluded from the review.

The General Medical Council (GMC) Guidelines (2010) on treatment and care towards the end of life indicated that if it is judged that Cardiopulmonary Resuscitation will not succeed in its aim of restarting breathing and circulation a Do Not Attempt Cardiopulmonary Resuscitation order should be put in place. The Guidelines considered whether it is appropriate to discuss the decision with the client as in some cases it might be burdensome to talk about an intervention that is clinically inappropriate. However, they did caution against withholding information because it is uncomfortable to the healthcare team. The previous GMC (2002) guidelines Withholding and Withdrawing Life-prolonging Treatment: Good Practice and Decision Making were challenged in court (*R (Burke) v. The General Medical Council* 2005). The case related to artificial nutrition and hydration but the principle stood that a patient did not have a right to treatment considered clinically inappropriate. In this study some of these interventions were carried out at the request of a relative rather than the resident, making the decision even more dubious. If the resident lacked capacity to agree to treatment and the treatment was not in their best interests this would in fact be unlawful (MCA 2005).

There were also examples of artificial nutrition and hydration being given to residents at the insistence of relatives, against clinical advice, again possibly not in their best interests and legally dubious. This topic was largely outside of the scope of this study.

Nevertheless, this was identified as an area with concerns from both an ethical and legal perspective and would be a worthy topic for future research.

7.2.3.7 Relatives' involvement

Relatives had limited input into everyday decisions as mentioned in 7.1. Although there were examples of staff involving relatives in delivery of care and some

During this study it was found that relatives varied in their involvement with residents' care and their reasons for wanting a particular level of involvement were diverse (see chapter 6, 6.5). It was rare for relatives to have spoken to residents about their wishes in the event of future illness. Clarence-Smith (2009) suggested that some relatives were

exhausted by the time of admission and were keen for staff to take over responsibility for residents' decisions. However, this study found that relatives varied in the involvement they wanted and many expressed frustration at the lack of information they were given. As with residents, relatives' assertiveness and expectations varied and some of this appeared to relate to their biographical history. It was noted in this study that the relatives who were most assertive in directing care were younger and educated professionals. As the numbers were small no definite conclusions could be drawn but future research in this area could be fruitful.

Some relatives felt obliged to be involved in areas of residents' lives, particularly their finances. Although some relatives held Lasting Power of Attorney for property and financial affairs, many did not and found themselves managing residents' affairs without legal authority. They often felt unsupported in this difficult situation and the staff in the Home did not consider that this was their responsibility. These issues were not considered in the reviewed studies and the issue of relatives managing the finances, of a person who lacks capacity, without legal authority, is a difficult issue and there needs to be investigation into how these people could be supported and residents' finances protected.

Staff did not always inform relatives about hospital admission in advance (see chapter 6, 6.2.2 and 6.2.3). Relatives said that they had not been asked about the resident's preferences and their biographical details, although staff suggested they were. Wheeler and Oyeboode (2010) found that staff reported that the involvement and informing of relatives was normal practice, with one caveat of a home where care workers were discouraged from discussing health and medical decisions with relatives and to leave it to registered nurses. However, Wheeler and Oyeboode (2010) only included staff as participants so a similar discrepancy to that discovered in this study of staff and relatives' beliefs may have existed.

Communication with relatives in the Home was found at times to be wanting. It was evident in this study that relatives often felt guilty about a relative entering a care home. Some reported that this made them feel negatively toward the Home at first. This was not mentioned by any of the staff. Train et al (2005) reported comments from staff that suggested they found relatives were unreasonably demanding and impossible to please, without the staff showing any understanding of relatives' psychological distress. This lack

of understanding of the difficult emotions relatives experienced was evident among many staff in this study. This issue is considered in the next chapter (8.5).

7.2.4 Strategies

Strategies were adopted by residents to permit them to make decisions and by staff and relatives that supported or sometimes thwarted residents in their decision making (See chapter 5, 5.3 and 5.4, chapter 6, 6.2 and 6.5). In this study there was evidence of some residents employing various strategies to retain control and, as in Cook (2008), there were signs that staff did not always recognise these. Tester et al (2004) also found residents asserting control and choices by adapting their environment and making complaints as strategies to maintain a sense of self.

Staff's strategies have been discussed throughout this chapter and were found to either support residents' opportunities to decide or restrict them. Relatives were often seen to support residents to make and enact decisions (see chapter 5, 5.4.3).

7.3 Key values in decision making in care homes

This section discusses the philosophical literature on the topic of the key values, autonomy and dignity and their relevance to decision making in care homes for older people. The research question of importance is; *To what extent is the policy and public discourse of values in decision making reflected in the practice of staff?* In health and social care, there has been a move away from a culture of paternalism towards one where the individual can make decisions and choices about their care and treatment. Dignity and autonomy are concepts which relate closely to choice and decision making. They appear in philosophy, bioethics and nursing ethics, professional codes for those working in health and social care, policy documents from the Department of Health (DoH) and equivalent bodies in Scotland and Northern Ireland, policies and mission statements of health and social care organisations and in the popular media. Many other values including, beneficence, non-maleficence, justice, paternalism and solidarity are also relevant to decision making but they do not feature in documents with either the strength or frequency of autonomy and dignity thus I have focused on these two values in this discussion. The empirical studies give an indication of normative practice, while this discussion considers how these values are perceived in the argument based literature before considering their operationalisation.

I have explored policy and legislation and the emphasis on autonomy and dignity in chapter 2, 2.7. Here I begin with a discussion on autonomy, its conceptualisation and value and whether there is an obligation to support it. There follows an exploration of what is meant by dignity and the relevance of autonomy and dignity to people with dementia.

Although they are frequently used in the discourse on health and social care, both concepts are often poorly defined. Whether they are concepts which are useful to direct the way health and social care should be delivered has also been considered. The influence these concepts have on practice as evidenced in this study is discussed.

7.3.1 The Conceptualisation of Autonomy

Autonomy has clear implications for decision making. The principle of respect for autonomy is what supports the idea that people should be allowed to make decisions about their lives and especially their bodies. Christman (2009) defined individual autonomy as being “one’s own person, to live one’s life according to reasons and motives that are taken as one’s own and not the product of manipulative or distorting external forces.” This is relevant in a care home when considering who decides, the resident or another person, how and why.

The latter part of the 20th century found philosophers such as Dworkin (1988) developing theories of autonomy and its practice. Autonomy is one of the four ethical principles from the much used text by Beauchamp and Childress (2009) which is now in its 6th edition and often used in the education of, amongst others, medical, nursing and social work students. Some authors, including Edwards (2009) and Gillon (2003), prioritised autonomy over the other principles giving it more weight, although Beauchamp and Childress (2009) did not concur, believing that all four principles; autonomy; beneficence; justice and nonmaleficence are of equal import and have to be balanced one against another. Autonomy has an important moral aspect in bioethics and is more than a mere theoretical concept.

Dworkin (1988, p6) identified the broadness of the way the term autonomy is used. He suggested it is used to mean liberty, self-rule and freedom of will. He sees it as equated with;

dignity, integrity, individuality, independence, responsibility and self-knowledge. It is identified with qualities of self-assertion, with critical reflection, with freedom from obligation, with absence of external causation, with knowledge of one's own interests...It is related to actions, to beliefs, to reasons for acting, to rules, to the will of other persons, to thoughts, and to principles.

Dworkin (1988 p20) conceived autonomy as;

a second order capacity...to reflect critically upon their first-order preferences, desires, wishes, and so forth and the capacity to accept or attempt to change these in light of higher-order preferences and values. By exercising such a capacity, persons define their nature, give meaning and coherence to their lives, and take responsibility for the kind of person they are.

This definition of autonomy excludes many people from being considered autonomous and makes many decisions made by 'normal' individuals, based on unconsidered first order desires, non-autonomous.

Beauchamp and Childress (2009) had difficulty with theories of autonomy which required high level reasoning or which must be governed by second order desires. They argued that this type of theory would place the concept above the ability of normal "choosers" making it an ideal rather than the autonomy experienced by individuals in their everyday life. More simply they saw autonomous choices as intentional, made with understanding and without controlling influences. They viewed autonomy as a matter of degree as the level of understanding and independence varies and is not either present or absent but along a scale.

Secker (1999) identified a different kind of autonomy referred to in bioethical texts as Kantian autonomy which found its basis in Kant's deontology. This centred on respect for persons and focused on rights rather than Kant's original concept of duty. She noted that respect for autonomy addressed in bioethics today is a very different idea than that originally intended by Kant. Unlike Kant, the conceptualisation by Secker (1999) did not equate autonomy with morality and allows the decision maker to consider other aspects than rationality such as "emotion, inclination, moral or other values, religious beliefs and/or the opinions of others..." (Secker 1999 p60).

Christman (2009) wrote of the need to separate basic autonomy or the ability to be “responsible, independent and able to speak for oneself” from the ideal of autonomy where the person is “maximally authentic and free of manipulative, self-distorting influences”. He asserted that basic autonomy is possessed by most adults who are free from debilitating pathology and not living under oppressive conditions. The ideal of autonomy in contrast may be achievable only by a few and is better perceived as a goal rather than an actuality.

The feminist view point also has the view that autonomy can be a difficult ideal as persons are not atomistic but socially embedded and their identity and view of self relates to relationships with others and society as a whole. Factors such as gender, class and race impact on self perception and consequently on decisions and autonomy. MacKenzie and Stoljar (2000) suggested that any society depends on cooperation and interdependence and this compromises the individualist view of autonomy. As Nedelsky (1989) stated, under the “conventional” view of autonomy the most autonomous person must be the most isolated. However, she intimated that relationships with others such as parents, friends, teachers and loved ones, help individuals to develop their autonomy rather than detract from it. She reconceived autonomy, recognising that there will always be tension between the individual and the collective which requires choice and compromise. Further, there is a need to move away from the idea of the isolated individual, threatened by the community. The community is constitutive of individuals and although it may be seen as a threat to their autonomy it is also its source. It is fallacious to divide individual and community due to the relational existence of all persons. Consequently, the types of human relationships that encourage the development of autonomy and allow it to thrive require recognition. A view of autonomy was proposed which was less individualistic and emphasised relationships. This is in keeping with residents in care homes being supported by both families and staff to maximise their autonomy, enabling them to retain control over their lives and care.

This view of autonomy can be described as “relational autonomy” which Mackenzie and Stojar (2000) argued is an umbrella term rather than a single conception. They suggested that these perspectives share the view that people are socially embedded and their identities are built through their relationships and “social determinants, such as race, class, gender and ethnicity” (Mackenzie and Stojar 2000 p4). The relational approaches consider the implications of the various social dimensions on identity, autonomy and agency.

Beauchamp and Childress (2009) believed that autonomy need not be excessively individualistic, neglecting the social nature of persons, nor excessively focused on reason, neglecting emotions, nor excessively legalistic, over emphasising legal rights to the exclusion of social practices and responsibilities. Even Dworkin (1988), who believed that autonomy requires second order capacity, did not suggest that the autonomous person needs to be substantively independent. In contrast to many philosophers' views on autonomy, he believed that a person can make an autonomous decision to allow another person to decide on their behalf. He indicated that the substantively independent view of autonomy conflicts with important values such as loyalty and commitment. This sits comfortably with the higher order preferences and values in his definition. If one has made a promise then has a desire to break it, the second order value tells one that it must be kept which is in keeping with the kind of person one is. Beauchamp and Childress (2009) did not see a person's choice to accept authority, for example the rules of a religion, as non-autonomous. A person can make an autonomous choice to submit to the rules of an authority.

There is a wide literature on the subject of autonomy so only a limited amount has been discussed here. Views vary with Dworkin (1988) holding that second order capacity is essential, on to Beauchamp and Childress (2009) who believed the "normal chooser" is autonomous. The feminist literature suggested totally independent choice is impossible, this is at least partly accepted by many contributors to the philosophical and bioethical literature. This does not mean that the concept of autonomy is compromised, just that human relationships and experiences influence autonomous choices. Some authors have reconceptualised the concept of autonomy to apply to older people in long term care settings, many of whom have dementia (Sherwin and Winsby 2010; Welford et al 2010; Nuffield Council on Bioethics 2009; Boyle 2008; Agich 2003). They have minimised or excluded the need for capacity to rationally weigh up information and make decisions normally associated with autonomy.

7.3.1.1 The value of autonomy

As Dworkin (1988 p6) noted, what all conceptualisations of autonomy have in common is that autonomy "is a desirable quality to have".

Dworkin (1988) suggested that autonomy has instrumental and intrinsic value. Instrumentally it allows a person to shape their own choices, making life more satisfying than if another made even benevolent decisions, as each individual is the best judge of their own interests. He further believed that individuals can derive considerable satisfaction from the process of deliberating, deciding and acting on their decisions. The intrinsic value of autonomy is that one is recognised as the kind of person able to determine their own destiny, and this can be tied to self-respect. Autonomous actions are conceptually linked to creativity, risk-taking, adherence to principle and responsibility. He consequently believed that these elements of a good life would be impossible without autonomy. However, with autonomy comes responsibility and the potential for blame and punishment. Thus, although there is value in autonomy it also has a converse negative element.

Dworkin (1988 p113) saw a special role for autonomy in health care: “because my body *is* me, failure to respect my wishes concerning my body is a particularly insulting denial of my autonomy”. Nor do feminist theorists, in spite of concerns about excessive individualism, deny the value of autonomy, believing it to be an important dimension of liberalism (Nedelsky 1989). Boyle (2008) considered the seminal work of Doyal and Gough (1991) which argued that autonomy was both a universal need and a human right, essential for well-being.

Autonomy is found in the literature on quality of life. For example, Kane (2001), in her work in nursing homes, identified autonomy as important to residents’ quality of life. Grundy and Bowling (1999) used well-being and autonomy as one of the three major domains of quality of life in their study on people aged over 85.

Although there is some doubt exactly what the term autonomy means, there appears to be agreement that it is something valuable. Autonomy can be taken from care home residents for benevolent reasons but, as Dworkin’s (1988) argued, this can make their lives less rich and lead them to be perceived in a more negative light.

7.3.1.2 Obligation to support autonomy

Respect for autonomy can be purely non interference in the lives, decisions and actions of others. However, I consider whether the duty to respect autonomy requires more than this.

an obligation to support people to make decisions on their own behalf and, once decisions are made, to assist individuals to execute those decisions.

Beauchamp and Childress (2009) identified respect for autonomy as including actions not merely attitudes. They saw it as not only non-interference but the responsibility to promote and maintain others' capacity for autonomous action and to diminish conditions disruptive to such actions. In health and social care this may involve providing information in a form comprehensible to the individual and enabling decision making by allowing sufficient time in an unthreatening environment. They saw the temptation for those in health care to perpetuate dependence rather than promote autonomy and believed that practitioners have an obligation to respect autonomy. Health and social care workers often need to assist executional autonomy as well as decisional autonomy as many older residents in care homes lack physical capacities.

In contrast to the usually held view that autonomy must be promoted, May (1995) warned that nurses should not promote autonomy in those who do not wish to exercise this "right". May (1995) opined that they could fail to respect the person's right not to be autonomous. The need to be accountable for decisions and actions that comes with autonomy may be an excessive burden to place on a person who is unwell or vulnerable. The meaning of vulnerability was considered in chapter 3, 3.4.2. It could be argued that the 'vulnerable older person's decision to let others decide is itself an autonomous decision. This is supported by Beauchamp and Childress (2009) who stated that there is a right to choose but no corresponding duty to do so. No one should be forced to receive information they do not want or to make a choice they would prefer to avoid, this would be inconsistent with the obligation to respect autonomy.

Doyal and Gough (1991) stated that autonomy is necessary to avoid serious harm. Boyle (2008), in response to this, suggested that the extant autonomy of care home residents, even those with dementia, should be promoted to avoid the possibility of mental ill health and poor quality of life. Thus, the conclusion can be drawn that autonomy is valuable and there is an obligation on others to provide support.

7.3.2 Operationalisation of autonomy

The authors who have written about autonomy in long term care (Sherwin and Winsby 2010; Welford et al 2010; Boyle 2008; Agich 2003) all argued that the liberal view of autonomy, i.e. negative autonomy or the freedom to be left alone, is insufficient in this context. Sherwin and Winsby (2010) posited that leaving a person who has reduced capacity alone may result in neglect. The difficulty is to find a balance between accepting valid refusal of care while providing necessary care to a person who lacks capacity. Sherwin and Winsby (2010) discussed society's negative attitude to dependence and old age and suggested that this negativity is internalised by residents, leading to a reduction of self worth and self trust which leads to diminution in their ability to exercise autonomy.

Agich (2003) noted that most understanding of autonomy concentrates on dramatic issues where people's rights are under threat, ignoring the everyday and mundane which is so central to long term care. Agich (2003) saw autonomy as a feature of everyday life going beyond the ideas of independence and non-interference. However, although he engaged with the problems of dependence in long term care, he drifted a long way from other theoretical views on autonomy, even from the literature on relational autonomy which is closer to his views. Once a concept is reconceptualised to this extent it may be more appropriate to use an alternative term and accept that autonomy does not apply to many dependent people living in long term care settings.

7.3.2.1 Autonomy and dementia

Dementia: Ethical Issues (Nuffield Council on Bioethics 2009) provided an ethical framework and considered how the concept of autonomy might be applied to people with dementia. They discussed, as I have here, the common definitions of autonomy and agreed with Agich (2003) that non-interference is insufficient as a response to respect for autonomy in the context of people with dementia and those living in most long term care settings. The report also perceived the importance placed on rationality as problematic. Emotional responses increase in importance as rationality fades. The emotional element of autonomy is likely to remain in a person with dementia when complex reasoning is no longer possible. The Nuffield Council on Bioethics (2009) argued that, whether this view of autonomy is accepted or not, it is still necessary to consider those desires and feelings a person with dementia expresses in the interests of their well-being.

The Nuffield Council on Bioethics (2009 p27), like Agich (2003), promoted active support for the person with dementia to “retain and express their sense of self”. Welford et al (2010) also suggested a conception of autonomy for older people in residential care which is wider than more traditional approaches. They conjectured that getting to know a resident, their biography and life plans, can enable them to be autonomous, even when cognitively impaired, right until the end of life (see the discussion on Nordenfelt on dignity of identity 7.3.4.1).

Autonomy can be difficult to reconcile with people with dementia, particularly in the later stages. Despite the reconceptualisation of autonomy discussed above which often suggested that even those who lacked mental capacity could be autonomous (e.g. Sherwin and Winsby 2010; Welford et al 2010; Nuffield Council on Bioethics 2009; Boyle 2008; Agich 2003), in the majority of writings, autonomy requires rationality and at least some understanding of the consequences of actions. Many everyday decisions and choices made or preferences expressed by residents had only minor consequences. Enabling these decisions showed respect for the person but it is less easy to suggest that this was the same as respecting their autonomy. Depending on the level of the dementia infrequent decisions, could only be made and executed with support from others. Although this assisted residents to retain some control over their lives, it might qualify as relational autonomy, but dependent on the amount of support needed the idea that autonomy can be claimed is doubtful.

7.3.2.2 Autonomy in this study

The discussion of risk in this chapter puts considerable focus on autonomy as a reason for taking responsible risks. None of the documents in the Home used the term autonomy. However, the Service Users’ Guide specified in the aims of the Home, the opportunity for residents to be involved in decisions about their care and to be subject to a minimum of rules and regulations. It stated that there was a culture that promoted responsible risk taking and that residents would be empowered to become involved in planning their own care and how services were delivered.

The strength and breadth of the discourse on autonomy is discussed above. As the term autonomy is so prolific in the philosophical, professional and policy discourse, it was surprising that the term was not used explicitly by any group of participants in this study. As Dunworth and Kirwan (2009) found, most workers appeared unaware, or at least

unable to articulate the ethical issues present in their everyday work. In this study there was also confusion between ethical dimensions and other responsibilities to obey rules and follow procedures. It was difficult to engage participants in discussion about values without them returning to more practical issues, (see chapter 6, 6.4).

Staff's fear of risk and how this impacted on residents' ability to make choices, thus potentially on their autonomy is discussed in section 7.2.3.2. The other situation where care workers overrode residents' choices was to deliver a minimum standard of care which they considered was their duty, at times mentioning residents' need for cleanliness to fit into the community.

Registered nurses did not mention autonomy either. In most cases, although they saw everyday decisions as something that residents could and should make for themselves, there were constraints (see 7.2.3). Where infrequent decisions were concerned, other factors often took priority. Hospitalisation of residents is a case in point and is discussed in chapter 6, 6.2.2. Some residents also considered that doctors wielded power over residents and staff alike, thus diminishing their autonomy, although this was not recognised by staff (see 7.2.3.6).

Relatives did not explicitly mention autonomy either. The relatives' role in promoting autonomy through support and advocacy was discussed in section 7.2.3.7. However, relatives being recruited by staff to persuade residents to comply with treatment, thus diminishing their autonomy are also considered in that section.

The concept of mental capacity was only mentioned once by a participant. None of the staff discussed the difference in the way they might react to residents according to their cognitive ability. Several care workers spoke of learning in training events that giving care that a resident refused would be classed as abuse but they were unable to explain the values that would authorise delivering essential care to residents who lacked capacity and refused care. Mental capacity was not discussed in any of the empirical papers reviewed. However, Manthorpe et al (2011) published a study outside the time frame of the review (chapter 2). In this they explored the implementation of the MCA in care homes through interviews with 17 senior staff and 15 care workers in 5 homes run by a single not for profit provider. They audited the participants' knowledge and familiarity with the Act. From this they concluded that care home staff knew very little about the Act and had

difficulty expressing what was meant by capacity. The MCA (2005) came into force in October 2007 and the study by Manthorpe et al (2011) was conducted in 2008. The evidence from the field work of this study in 2010 found that the concept of capacity and the MCA still had not penetrated practice. Manthorpe et al (2011) considered that staff were often working in the spirit of the Act at least in relation to residents' choices relating to their everyday lives. This study in contrast found that although staff generally professed a desire to offer choice as the MCA requires, in practice this was often overridden by risk aversion which knowledge of the Act could moderate. Knowledge of the Act, its implementation and education that is provided and the gaps need examination (see chapter 8, 8.9.2 and 8.9.3).

In the Home, the discourse on allowing residents involvement in decisions about their own care in the Service Users Guide appeared not to have penetrated practice. Staff understood that residents had a right to make decisions and that their preferences needed to be canvassed. In situations in which the consequences were perceived to have less significance, decisions by residents were usually respected regardless of mental capacity. Rarely, these decisions were overruled by staff to provide a minimum level of care. More often decisions were challenged if a person was considered to be at risk of harm from their actions. Resident autonomy, choice or preference regardless of their mental capacity was subsumed beneath the staff's fear of risk of harm. Many risk assessments were performed routinely, for pressure ulcers for example, but action taken to reduce risk was not tempered by residents' opinions on the best course of action. Although there were occasional examples of sensitive negotiation with residents where they wished to take risks, in general there was a risk averse culture in evidence (see chapters 5, 5.4.4.1 and 6, 6.2).

Respect for residents' autonomy did not appear to be a guiding value among staff in the Home. This philosophy already exists in the Home's Users' Guide but was not translated into practice. Whether it would have made staff put more store on residents making their own decisions if they considered respect for autonomy more is uncertain. It would depend on which definition of autonomy they understood and whether it was strong enough to overcome other values such as beneficence, non-maleficence and duty of care. Based on these findings I have made recommendations for policy, research and education and these are presented in chapter 8, 8.9.1, 8.9.2 and 8.9.3.

The final aspect in relation to autonomy concerns staff. In this study it was found that staff, particularly care workers, lacked autonomy in their practice and did not see it as their role to make decisions (see chapter 6, section 6.2). Registered nurses made more decisions but their options were restricted by the rules and policies of the Home. Thus, the organisational constraints restricted the autonomy of all staff.

It is easy to see how, when staff members' autonomy is restricted, this is not be an ideal environment for staff to facilitate residents' autonomy. Wheeler and Oyeboode (2010) identified homes where there was strict demarcation of roles and care workers were excluded from planning decisions and even handovers. They found, from staff comments, that optimal care could best be facilitated by teams meeting together, forging team goals and everyone's contribution being valued (see chapter 8, 8.9.2 for recommendations).

7.3.3 Conceptualisation of dignity

Dignity has been added along with autonomy as it relates, not just to residents making their own decisions, but also to decisions made for residents by others. The process of decision making, those who make them and the values underpinning them can affect a resident's dignity as well as the dignity of staff and residents' families and friends.

Like autonomy, dignity is not an easy concept to define. In the DoH (2006a) Dignity Challenge, of the ten points that define a service that respects dignity, the most obviously applicable to this study on decisions and choice is to "Enable people to maintain the maximum level of independence, choice and control." As this discussion on dignity will demonstrate, although it is a slippery concept, most attempts to pin it down include autonomy and choice as central parts of its meaning.

Autonomy and dignity are often linked in the literature. For example, Pinker (2008) suggested "because it amounts to treating people in the way that they wish to be treated, ultimately it's just another application of the principle of autonomy", whilst Welford et al (2010) named respect for dignity as an antecedent for autonomy.

Macklin (2003) commented that dignity was a useless concept. It was her belief that it meant little more than respect for the person and their autonomy, the need to obtain consent, keep confidentiality and avoid discrimination and abuse. She believed it added

nothing to the debate on ethical care. Pinker (2008) made it clear that without a definition the concept could, and has been, used to make any number of arguments with no scientific or empirical background. Commentators rely on the reference to human dignity as a universally recognised good. Pinker (2008) argued that it is often used in a way that referring to autonomy would suffice. He considered dignity to be a confusing concept, relative and subjective.

There have been a number of attempts at clarifying the concept of dignity in the nursing literature (Anderberg et al 2007; Coventry 2006; Jacelon et al. 2004; Fenton and Mitchell 2002; Marais 1994). Although these works suggested that the concept applies to all, the definitions largely identified subjective feelings, autonomy or at least an ability to make choices. Shotton and Seedhouse (1998) wrote of capability and competencies without mentioning those who do not have them. They saw indignity as an experience, suggesting that if it was not felt it could not exist. Thus it appeared that one could not be undignified if one did not experience it.

Marais (1994) in her attempt to clarify the concept in professional practice found self advocacy an antecedent of dignity. This suggested that for a person to have dignity they must have at least some level of rationality. She suggested that even during undignified procedures, if a person had been allowed self-advocacy and gave consent they can maintain their dignity. Other antecedents identified were, dignity demonstrated in behaviour, speech, conduct and dress and dignity developed through life experiences. All of these aspects may be reduced or even lost as dementia progresses. Further, Marais (1994) agreed that indignity only exists if it is experienced by the individual. She even proposed that loss of dignity might be assessed by measuring physiological changes, such as skin temperature rise which occurs during blushing. This again may be unhelpful when considering people with dementia.

It is therefore necessary to explore whether there is an alternative way of viewing dignity that includes every person receiving care regardless of their ability to perceive 'indignity'.

The large pan-European project, Dignity and Older Europeans (Tadd 2006) spanned six European countries to establish what was meant by dignity and how it could be applied to the care of older people. They combined theoretical components with empirical elements to develop a model of dignity, educational materials and policy and service

recommendations intended to influence the care of older people across Europe. From this study came a more comprehensive view of dignity (Nordenfelt 2009). He identified four types of dignity, *Menschenwürde*, dignity as merit, dignity as moral stature and dignity of personal identity.

Menschenwürde is the dignity which resides in every human being, it is intrinsic and universal. Other types of dignity are present in varying degrees. Dignity as merit is the special dignity bestowed on an individual by society, e.g. by an appointment. The position and the dignity of these individuals brings rights. Dignity of moral stature relates to the individuals' self-respect based on living one's life in a moral way. Respect and dignity can also be given to the moral individual by others and society, although it affords no automatic rights. Nordenfelt's final type of dignity is that of personal identity.

Components of this type of dignity include integrity, physical identity, autonomy and inclusion. He also suggests that there may be a specific type of dignity unique to older people including the dignity of merit of wisdom and the dignity of achievement and effort, which can only be gained by leading a long life. However, many of these issues could lead to people being thought of as more dignified if they had achieved more in their earlier life, suggesting that the treatment of older people may vary according to their achievements, which is incompatible with the normal principles of care.

Woolhead et al (2004) found that dignity was viewed by older people in the UK as multifaceted, the facets being, dignity of identity, human rights and autonomy. Dignity of identity focused on how it affected the self, in relation to other age groups and in relation to health care personnel. Human rights included the universal concept of human dignity, being treated as an equal whatever one's age and the right to choose how one lives and dies. Autonomy is the retention of independence and control over one's life.

The Social Care Institute for Excellence Guide 15: Dignity in Care (2010) defined dignity in relation to self-respect which might not be useful in the care of people with later stage dementia. However, the Dignity Challenge, launched in 2006, (Dignity in Care Network 2012) gave ten points necessary in the provision of good quality care that respects people's dignity. This included points which are relevant even to those who may not be in a position to experience indignity through an erosion of their self-respect. Despite the contradiction between the definition and the points identified, this may still be more useful in practice than grappling with the idea of a universal definition of dignity.

One other perspective on dignity worthy of consideration is the dignity of the person who provides the care. Gallagher et al (2008) addressed Aristotelian virtue theory indicating that nurses are required to both treat those in their care with dignity as well as comporting themselves in a dignified manner. Dignity of moral stature (Nordenfelt 2009), could apply to the behaviour of the care provider and this may well be useful when considering the care of people unable to perceive indignity themselves.

7.3.4 Operationalisation of dignity

As discussed earlier, the majority of people who live in care homes have dementia (POST 2006). Consequently, it is important to consider how the concepts of dignity and autonomy apply to this large group of residents. It cannot be assumed that people with dementia do not experience violation to their dignity and this needs consideration especially when residents' behaviour challenges the staff caring from them. The difficulty of finding a definition of dignity that applies to all care home residents regardless of their ability to perceive indignity has been discussed. There have been some definitions which have aimed to include all recipients of care regardless of their cognitive ability. I continue by considering dignity in relation to this study.

7.3.4.1 Dignity in this study

The term dignity was not mentioned by any participants in this study. Few of the empirical studies, identified in the literature review, reported any comments using the word dignity made by participants (Train et al 2005 was an exception). However, in this study many of the components of the concept, as it has been discussed above, offering choice, privacy, respect for the person etc., were evident in care delivery and the discourse of all participant groups. Scott, Välimäki, Leino-Kilpi et al (2010), for example, focus on autonomy, privacy and informed consent, all of which it can be argued, relate to dignity.

One type of dignity named by Nordenfelt (2009), dignity of identity resonated with the findings of this study, although the other components lacked relevance. Nordenfelt (2009) suggested that there are ways in which dignity can be applied to everyone regardless of ability. *Menschenwürde* applies to every living human being and he states that it "cannot be lost as long as the person exists" (Nordenfelt 2009 p xii). This indicated that the way a person is treated would not affect this type of dignity so does little to guide how care can promote dignity, or whether there is such a thing as undignified care. As was mentioned

above (7.3.3), dignity of merit and dignity of moral stature both suggest that some people would have higher levels of dignity which could lead them to be treated differently which is not generally considered appropriate within a care environment.

Dignity of identity however, could be applied to people even in the later stages of dementia. The continuity of personhood which reaches from the identity of the person while they still had capacity through to when they are in the later stages of dementia, would allow the person to retain their dignity of identity. Thus, the care they receive could promote or reduce this. Maintaining identity was identified by My Home Life (2012) as a best practice theme. Nordenfelt (2009) labels this type of dignity as what a person attaches to themselves as a whole integrated person with relationships to others and a past and future. It is embedded in the physical body, the way they live their life and how they perceive themselves in the culture in which they live.

Residents in care homes can have this type of dignity diminished due to loss of roles and social relationships. Frail older people reconstructing their lives within care homes (see Cook 2008) could be said to be engaging in what Öhlander (2009) called “identity work”. He suggested that “Every act, however small and insignificant it might be, is at the same time an act of communicating, elaborating and negotiating identity.” (Öhlander 2009 p80). As residents in this study have attempted to make decisions or express preferences, and even when they chose not to, they were communicating something about themselves and their identity. Öhlander (2009) believed that identity work can uphold dignity and may be called dignity work.

So far I have considered residents maintaining their own identity and dignity. Örluv and Nikku (2007 p509) identified the need for those working with people with dementia to engage in dignity work, as many capacities decline “physical social and cultural”, as the disease progresses. Similarly Kitwood (1997 p89) referred to “positive person work” as the basis of good dementia care; “strengthening a positive feeling, nurturing an ability, or helping to heal some psychic wound”. Tester et al (2004) considered the retention of a sense of self as an important issue for residents’ quality of life. Staff can, and in this study often did, assist residents with retaining their identity, especially when staff encouraged residents to communicate their wishes. Some staff had significant knowledge of residents’ past lives and families which they talked about to residents, validated their identities and roles both past and present. However, many staff knew little about the history of residents

and considered it irrelevant. Relatives were not always encouraged to discuss the residents' past lives which was a barrier to staff maintaining residents' identity and thus their dignity of identity. Staff in the study by Wheeler and Oyeboode (2010 p20) declared that, "family were an invaluable source of social history and information to aid care planning" but as in this study resident involvement was not always sought. In this study, one resident also said that the staff did not know about her past life but thought that she could not expect it to make a difference. Thus, some staff were engaged in identity work, although they did not recognise it as such, others were not and did not consider this as part of their role.

In later stages of dementia it is uncertain whether dignity of identity remains a useful concept. Nordenfelt (2009 p33) wrote of integrated and autonomous persons and, as has been discussed already, autonomy is not always associated with people with severe dementia. Relatives were aware of the change in residents as they became more dependent. The maintenance of a continuation of identity may be more important to relatives than to residents. At times there was evidence that residents' current preferences may have differed to those prior to the onset of dementia. Dworkin (1993) considered the concepts of experiential interests versus critical interests. Experiential interests are those preferences and desires that provide comfort and pleasure in the present. Critical interests are those that span people's lives. They are about the type of integrated life they would like to live, incorporating their character, values and relationships. Dworkin (1993) believed that as a person with dementia is the same person they were before, their overall life plan, expressed in their critical interests are more important than the experiential. He believed that rejecting current preferences in favour of critical interests does not affect a person's dignity. Consequently, he suggested that dignity would best be maintained by following people's previous wishes to support their critical interests. Dignity of identity for those with severe dementia shares characteristics with Dworkin's (1993) promotion of critical interests. As this study showed care workers stating that giving care to residents who resisted was abuse, continuity of personhood and critical interests would give authority to staff to provide the care they considered necessary, keeping people clean for example, even when it is not what the resident appears to prefer at the time.

The Commission on Dignity in Care (2012) was set up in response to reports of undignified care in hospitals and care homes. They have issued an interim report for consultation "Delivering Dignity". This is an interesting and informative report providing

recommendations on how best practice can be implemented across the health and social care sectors. Although it is about *how* care and treatment should be delivered rather than *what* care and treatment, it is still unclear what they conceive dignity to mean. They emphasise the importance of resident involvement and choice amongst many other areas of practice.

Also published recently, the report in Northern Ireland by the Human Rights Commission (2012) is entitled “In Defence of Dignity: The Human Rights of Older People in Nursing Homes”, similarly fails to define dignity. The title implies that dignity and Human Rights are analogous and the term is used to mean many different things. These two new documents (Commission on Dignity in Care 2012 and Northern Ireland by the Human Rights Commission 2012) are no clearer on what is meant by dignity despite the many attempts to define the concept. In contrast, a ‘dignity code’ has been put forward by the National Pensioners Convention (2012), intended to “uphold the rights and maintain the personal dignity of older people’. This provides a clear list of practices and actions they consider are unacceptable to older people such as;

- Being abusive or disrespectful in any way, ignoring people or assuming they cannot do things for themselves
 - Treating older people as objects or speaking about them in their presence as if they were not there
 - Not respecting the need for privacy
 - Not informing older people of what is happening in a way that they can understand
 - Changing the older person’s environment without their permission
 - Intervening or performing care without consent
 - Using unnecessary medication or restraints
 - Failing to take care of an older person’s personal appearance
 - Not allowing older people to speak for themselves, either directly or through the use of a friend, relative or advocate
 - Refusing treatment on the grounds of age
- (National Pensioners Convention 2012)

They have launched an e-petition (HM Government 2012) calling for the adoption of the code. This dignity code is a very practical approach to the issue.

As Gallagher (2011) stated, the empirical literature on dignity continues to grow. She expressed concern that there remains a disconnect between the philosophical literature and the empirical work on dignity in care. In this study, what was evident was that there was a

disconnect, but between all that is written about dignity whether, philosophical, empirical or policy and what happens in practice. I would suggest that this is more important if the aims of those who work in health and social care ethics is to improve the experience of the recipients of care. The implications and recommendations of these findings in relation to dignity are discussed in chapter 8, section 8.9.1

Extending the discourse on dignity and autonomy, two of the key values in decision making in the care of older people, is evidently important to a study on decision making in a care home. The terms however, are often poorly defined and, where they are defined, definitions vary dramatically. This lack of clarity can be a barrier to the concepts being used to improve practice.

7.4 Autonomy versus Utility

As the earlier discussion suggests, autonomy in long term care is difficult to reconcile. Agich (2003 p1) purported that autonomy and long term care “are a remarkably paradoxical conjunction”. This is because those needing long term care lack the independence, and sometimes the rationality, that are central to the concept of autonomy evident in much of the bioethical discourse. Agich (2003) indicated that the vulnerability of those receiving long term care means that they will likely benefit from the rights which autonomy promotes. Thus, although the idea of promoting residents’ autonomy is attractive it lacks practicality in the environment of long term care, due to residents’ need for support and, in many cases, their lack of mental and physical capacities.

The complex situation in this study had several conflicting perspectives and a tension was identified. Staff considered that residents had a right to make their own decisions, and that their wishes should be central to care delivery. However, due to the difficulties of providing care for a group of people with differing needs and with limited resources, routines were put in place for ease of providing care for all. In this study one member of staff discussed the necessity of basic care to keep residents smelling sweet for the benefit of the community. Although this could be seen as overriding a resident’s right to refuse care, the Northern Ireland Human Rights Commission (2012) suggested that the provision of personal care is necessary in the preservation of dignity. This provides further confusion for staff untrained in ethical problem recognition and solution.

Staff often took passive acceptance of care home practices as a resident's choice. However, as has been discussed above, this may have been learned helplessness (Seligman 1975) rather than real willingness to accept the way care was delivered. Further, many staff prioritised avoidance of risk above choice. They often considered this their duty but fear of blame concerned individual members of staff and they also showed concern for the reputation of the Home. Relatives also were sometimes paternalistic towards residents, doing what they believe to be in their best interests, at times disregarding residents' wishes regardless of their mental capacity. Many relatives suffered guilt at being unable to care for the resident at home thus, through their involvement, they attempted to alleviate their guilt.

These issues demonstrated a tension between the need to hold the residents' needs and choices at the centre of care and the need to run a care home smoothly and use resources to provide the best care for the community. The community, which was the Home, was concerned with providing good, safe care to all its residents. It also needed to be perceived to be doing so to maintain their reputation. The majority of care homes, including St Bernadette's, are run for profit and any bad publicity can affect admission to the home and thus, the 'bottom line'. Staff numbers need to be sufficient to provide satisfactory care but within limits which keeps the home financially viable.

Heteronomy was also evident amongst the majority of staff, procedures and regulations were the focus of their discourse rather than ethical dilemmas. Kant (1959) suggested that a heteronomous will is one governed by rules externally legislated. The will submits to an end, to receive pleasure, searching personal perfection or appeasing their moral sense. Kant perceived heteronomy as non-moral. (neither moral nor immoral). Heteronomy was evidenced through the lack of autonomy experienced by staff and their willingness to comply with rules without question.

Care homes consist of a community of residents, their relatives and the staff. Although the purpose of a home is to care for residents, others with a stake spend considerable time and invest emotionally as well as practically. Consequently, the home is run in a way that provides an organisation in which all stake holders can feel comfortable and allowing it to remain financially viable. In this study, constant tension for staff was noted between the need to support residents' autonomy and opportunity to make choices and to cope with the needs of others and the organisation. This utilitarian view was not recognised by

participants as the discourse differed from practice. Lack of recognition could help with the dissonance that might otherwise be experienced by staff.

7.5 Solidarity

Autonomy and dignity are important in care delivery and elements of the concepts were found to be important in this study. A complementary concept to autonomy and dignity is that of solidarity. Autonomy, if perceived as residents being able to make their own decisions and choices, was found to be limited by a number of factors. These included residents' characteristics such as cognitive and physical impairment and their lack of assertiveness, staff's communication ability and their attitudes, beliefs and strategies and their fear of risk, low staffing levels, routines systems of policy and lack of relative involvement. Solidarity as a concept, through its promotion of relationships between stakeholders, provides promising ideas of how to manage the tensions between the conflicting demands upon staff found in this study. Solidarity requires support for autonomy through the relationship between all those who live work and visit the home without ignoring the needs of others. Dignity of identity (Nordenfelt 2009) was found to be relevant in this study and could be supported through the promotion of a more collaborative approach between residents their relatives and staff under the umbrella of solidarity. Neither autonomy nor dignity allows for the needs that have been identified of relatives, staff and the providers who need to run a financially viable business, thus the addition of solidarity to the mix of values could help to improve care, raise job satisfaction for staff and enhance the experience relatives.

Solidarity is not used in the literature or policy with the frequency of autonomy or dignity but has recently entered the discourse in the sphere of medical ethics (Prainsack and Buyx 2011). The principles approach, most notably the text by Beauchamp and Childress (2009), has been dominant in recent years and as Callahan (2003) suggested it reflects the individualistic culture in which it was developed. Solidarity (Prainsack and Buyx 2011), relational autonomy (MacKenzie and Stoljar 2000), ethics of care (Held 2005) and feminist theory (Nedelsky 1989) all consider the individual within their social and societal context. This would be particularly useful where the concept of autonomy and the elements of dignity relating to autonomy and rational decision making are difficult to apply.

Solidarity, like autonomy and dignity, is poorly defined. Nonetheless, Prainsack and Buyx (2011) in their report, commissioned by the Nuffield Council for Bioethics, note that solidarity is appearing more frequently in public discourse, although the references in the biomedical ethics literature remain scarce.

The definition of solidarity provided by Prainsack and Buyx (2011) is in three tiers. The lowest level is the interpersonal, it comprises of “the willingness to carry costs to assist others with whom a person recognises a sameness or similarity in at least one relevant respect” (p47). This would exist amongst family members, friends, neighbours and colleagues. However, they also suggest that solidarity will be enacted towards the most vulnerable individuals as an individual recognises in the vulnerable person, a fellow human being and perceives their own past or future vulnerability and need.

The second tier is group practice. This is where a solidaristic practice is seen as good conduct and becomes the norm. It is “a collective commitment to carry costs to assist others (who are all linked by means of a shared situation or cause)” (Prainsack and Buyx 2011, p15). They suggest that this is the most prominent tier and those in a similar situation share risks and positive goals. Members of the group negotiate conduct working toward their common goal. This tier can be particularly applicable to a care home where residents, their relatives and staff could come together to operationalise a shared philosophy. The Nuffield Council on Bioethics (2009) considered that solidarity was a useful concept in the care of people with dementia. It suggested that solidarity underpins the duty to recognise mutual interdependence and responsibility and of people and society to support those with dementia and their carers. They saw solidarity on a number of levels. Aside from society’s obligations, there is the need to support families and friends who want to maintain their personal solidarity with a person with dementia. Also, it is necessary to show solidarity with care workers who need support and recognition to develop and maintain good relationships with residents, their relatives and other staff and to provide good care.

The final tier identified by Prainsack and Buyx (2011) was contractual and legal norms. This level included examples such as contracts between actors, the welfare state and international treaties. There is a legal contract between care home operators and their residents and many residents receive funding from the welfare state. Prainsack and Buyx (2011) stated that the higher tiers cannot exist without the lower tiers, although lower tiers

can exist independently of the higher tiers. The welfare state only exists because of solidarity between individuals who recognised the vulnerability and need of fellow human beings.

The concept of solidarity involves elements of mutuality and reciprocity which Bowers et al (2011) reported is poorly recognised in care homes, by the public, with older people being perceived as passive recipients of care to whom mutual and reciprocal support is irrelevant. In this study residents were seen to have relationships with each other which provided mutual social and psychological support. Some residents also did small tasks around the Home, laying the table for lunch for example, providing them with meaningful activity, while saving staff time. There were examples where relatives gained pleasure and advice and support from residents, as well as enjoying the memories of the long relationship they had shared. Where residents and relatives recognised staff's efforts and validated their feelings about their work, this was supportive and raised job satisfaction. These issues could be capitalised upon, putting solidarity into the forefront of care.

In the recent document by the Commission on Dignity in Care (2012), there are many elements which could be construed as solidarity. It considers that a care home is a community and makes recommendations in relation to residents, relatives, staff and management all of whom need support if what they consider to be 'dignified care' is to be delivered. This document implies that, under the vague usage of the term dignity, the value of solidarity is included.

A care home is a community consisting of residents but also of their visitors and the staff. This study showed, as others had before, that there was often a lack of understanding between the groups. There was often a lack of empathy on the part of staff towards relatives. Relatives generally recognised that the staff's work was difficult and poorly paid. However, that they had to do this work with little training and education and often a poor grasp of the British cultural and legal systems was not addressed. The RCN (2012a) identified lack of training as one of the major concerns of staff employed in care homes in England. It also reported that many staff felt that care home managers failed to utilise the skill and experience of frontline staff and left them feeling unsupported. Kitwood (1997) also argued that the well being of staff will affect the care they provide to residents so organisations must take care of their staff for the benefit of all. Solidarity, with all parties

seeing themselves as ‘all in it together’. providing mutual support and understanding is a way forward.

The Patient and Client Council of Northern Ireland (2012) has recently launched an advocacy toolkit for the care home sector. The aim is to develop “partnership between residents, relatives, care home staff and individual (professional) advocates”. (Patient and Client Council 2012 p1). It is established that there are several models of advocacy and the right model will depend on the individual. Whilst all models aim towards self advocacy (which might be called autonomy), citizen, group or collective, peer and individual (professional) advocacy all require solidarity. As recipients of care, residents sometimes need someone to stand up for their needs and solidarity is a value which supports this. Independent advocates are also recommended in the NHS Confederation (2012) document, “Delivering Dignity”. Although this is valuable it does not include recommendations for the many forms advocacy can take, bringing in someone from outside is only one.

In relation to residents with dementia both autonomy and dignity have been shown to have limitations. Kitwood (1997) reported that Post (1995) adopted a principle he called ‘moral solidarity’. He suggested that all humans are united and regardless of a person’s mental capacity the link remains unbroken. The recognition of a person with dementia, whether as a fellow human being or a member of the care home community, offers solidarity as a useful value in their care.

Prainsack and Buyx (2011) report that solidarity is linked to the way society functions and where the boundaries of responsibility exist, and should exist between individuals, families, the community and society. Ethics in western society have become more individualistic whereas this move towards a dialogue on solidarity is a move towards a more mutual responsibility for the care of the most vulnerable in society. many of whom are resident in care homes.

7.6 International Literature

This study has focused on long term care in the UK. A rapid review (see discussion of method in Watt et al 2008) of empirical studies in long term care settings was undertaken of the international literature since 2000 using the same search terms and data bases as in the UK review (See chapter 2, 2.4). As identified in the review in this thesis much of the literature is located in settings other than long term care, for example Cabete (2012). in her Portuguese study, considered hospitalised older people and the divide between latent autonomy and manifest autonomy. The studies identified in the review of international literature are summarised in table 3.

Table 3 International studies

| Author & date of study | Country where study took place | Method(s) used | Setting & participants | Study aims |
|-----------------------------------|--------------------------------|------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------|
| Barkay and Tabak 2002 | Israel | Questionnaire | 1geriatric center, 2 wards, 39 residents | Describe& evaluate the degree of autonomy, participation & well-being of frail elderly residents. |
| Bolmsjö, Sandman & Andersson 2006 | Sweden | Observation | 1nursing home ward, 12 residents | Describe & interpret the ethical milieu & analyse ethical situations. |
| Bourret et al 2002 | Canada | Focus groups | 3 long-term care facilities, 20 residents, 15 nursing staff | Generate knowledge about mobility from nurses' & institutionalized perspective. |
| Cabete 2012 | Portugal | Biographical interviews, biographical seminars, oral & written narratives and nurses' diaries. | Acute care settings in 1 general hospital, 16 hospitalized older people, 1 academic institution 20 nurses. | Explore the concept of autonomy and empowerment in hospitalized older people from the perspective of nurses and patients. |
| Chan & Pang 2011 | Hong Kong | Semi-structured interviews | 4 care and attention homes, 42 Chinese frail older people | Identify approaches to end of life decision making. |
| Chisholm, Jenson & Field 2011 | New Zealand | Observation | 50 aged-care residential facilities | Investigate foodservice, menu and meals & identify promoters & barriers to optimal nutrition. |
| Dran 2004 | USA | Interviews | 18 family members, 23 aides | Discover whether knowledge of pre-admission life related to how the resident and work with the resident was perceived. |
| Dreyer, Forde & Nortvedt 2009 | Norway | In depth interviews | 10 nursing homes, 15 relatives of 20 patients | Focus on protecting patient autonomy & how relatives perceived their role as substitute decision makers. |
| Forbes, Bern-Klug & | USA | Focus groups | 4 nursing homes, 28 family | Describe families' decision-making processes regarding end |

| | | | | |
|--------------------------------------------------|-------------------------------------------------------|--------------------------|--------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------|
| Gessert 2000 | | | member of residents with moderate or severe dementia | of life treatments. |
| van der Heide et al 2007 | Netherlands | Questionnaire | 5,342 physicians | Follow up study to assess the effects of the 2002 Dutch law changes & the reporting rates for euthanasia & assisted suicide & reasons for non-reporting. |
| Hikoyeda & Wallace 2001 | USA | Interviews & observation | 20 facilities, 57 residents and relatives | Examination of how ethic specific features in care facilities meet residents needs/preferences & affect quality of life (QoL). |
| Iris, DeBacker, Benner, Hammerman & Ridings 2012 | USA | Mixed methods | 240-bed skilled nursing facilities sample sizes varied by group and task | Understand stakeholders' view of QoL describing key elements & develop standardised assessment instrument for person-centred care planning. |
| Lane & Harrington 2011 | Australia, Hong Kong, Israel, Switzerland Taiwan, USA | Literature review | Hospitals and aged care facilities, people aged >60 | Identify factors influencing nurses' use of physical restraint. |
| Suhonen et al 2011 | Finland | Questionnaires | 4 long-term care hospitals, 147 staff | Explore nurses' perceptions about individuality in older people's care. |
| Sydner & Fjellström 2005 | Sweden | Participant observation | 4 elderly care centres | Study how organizational structure & staff's routines and actions influence food related activities. |
| Välimäki, et al (2008) | Finland | Questionnaires | Student nurses pre (n=120) & post (n=115) clinical training in long term care institutions | Compare nursing students' perceptions of self determination in elderly patients before and after clinical training. |

It was evident that some national policies stated the importance of older residents in long term care having their autonomy supported and being offered choices in their care and treatment. For example, Välimäki, et al (2008) noted that the Finnish National Framework for High Quality Care and Services for Older People recommended that services should support quality of life, self determination and independence.

As identified in this UK study, there is empirical evidence from other countries that residents in long-term care settings desire autonomy and choice and that this can improve their quality of life, from Israel (Barkay and Tabak 2002). Sweden (Bolmsjö, Sandman

and Andersson 2006), the United States of America (USA) (Iris et al 2012: Hikoyeda and Wallace 2001).

In addition, studies identified from New Zealand (Chisholm, Jenson and Field 2011) and Sweden (Sydner and Fjellström 2005; Bolmsjö, Sandman and Andersson 2006) mirrored the findings in this study that autonomy was not always respected and choices were not universally offered. Many of the reasons for the gap between the recognition that autonomy and choices are important to residents and their delivery resonated with the findings of this study. Some of the barriers to autonomy and choice included poor staffing levels reported in Sweden (Bolmsjö, Sandman and Andersson 2006), residents' characteristics including mobility reported in Canada (Bourret et al 2002) and language impairment reported in the USA (Dran 2004) and staff routines reported in Finland (Suhonen et al 2011).

Staff values, attitudes and characteristics which affected how much choice and autonomy was given to residents were found to be significant in a study from Finland (Suhonen et al 2011) as they were in this study. In line with this study, the involvement of relatives was also found to be important in decision making in care homes but involvement was often not maximised as reported in studies from Finland (Suhonen et al 2011), Norway (Dreyer, Forde and Nortvedt 2009) and USA (Dran 2004). Risk was also identified as a reason for restricting residents' choice and autonomy. However there were differences in the way risk was managed for example the use of physical restraint on elderly people was common in long term care settings in many countries as reported in the thematic literature review by Lane and Harrington 2011.

In line with the findings of this study there was often reported conflict between the desire of staff to deliver choices and promote resident autonomy and the needs of other residents and the organisation. This was reported in studies from Finland (Suhonen et al 2011) and Sweden, (Bolmsjö, Sandman and Andersson 2006).

Advanced decisions are also discussed in the international literature. One of the major differences regarding end of life decisions exists in jurisdictions where euthanasia or assisted dying is legal such as the Netherlands (see van der Heide 2007). However there were more similarities than differences between the findings in this UK study and the

literature from the USA (Forbes, Bern-Klug and Gessert 2000) and Hong Kong (Chan and Pang 2011).

One of the important findings in this study related to residents' capacity and its effect on decision making and autonomy. This issue was not evident in the international empirical literature.

There was a resonance between the findings of this study and the international literature suggesting similarities in underlying principles. However most of the studies were small scale qualitative studies with limitations to their generalisability. International comparative studies would be of value to explore the similarities and differences between different countries in decision making in care homes.

7.7 Strengths and Limitations

Some of the findings of this study confirmed previous evidence. However, the methods used in this study have both widened and deepened the evidence base. This study included three groups, residents, relatives and staff, only 2 studies identified in the literature review also included these 3 groups, (Train et al 2005 and Jones and Manthorpe 2002). Neither study had the aim of considering decisions and choice although these topics were identified in their findings. Train et al (2005) only studied residents with dementia while Jones and Manthorpe (2002) did not include residents with cognitive impairment, neither study considering how the diversity of residents could affect choice. This study used interviews, informal conversations, observation and documentary analysis. Only Tester et al (2004) used observation, they used a variety of creative methods to engage people with cognitive impairment but they only studied the residents' perspectives. None of the studies involved long term engagement with participants in one home where in depth relationships were developed. This was a major strength of this study as it was possible to return to participants throughout the study to check the interpretation of their previous responses and to observe situations that had been identified through other methods.

The study also had some limitations. The use of a case study, although having the advantages outlined above, leads to questions of generalisability of the findings to other homes. In this instance the Home was selected for its size as representative of the national

average number and diversity of residents, including those with and without cognitive impairment and some needing nursing care while others only required social care. Other characteristics of the Home, such as the staffing levels were typical for one of its size. The findings have also been used to generalise at a theoretical level. A second limitation was the level of public involvement in the study. On reflection it would have been appropriate to have consulted interested parties in a care home to assist with the study design and possibly with the running of the study and the analysis however, there was a lot of engagement with participants throughout the study.

A third limitation was the effects of social desirability. I was concerned about the veracity of interview responses and whether what I observed was the same as the practice when I was not present. There was a risk, particularly with staff, that participants would talk of what they considered good practice rather than giving a realistic picture. Groves et al (2004) identified the social desirability bias, where participants respond to questions with the way they believe they ought to behave rather than how they do behave. In this study the use of multiple methods and more than one group of participants helped me gain a fuller picture and reduce this bias. Staff at times talked of more ideal practice than was observed or reported by other participants. However, it appeared that this was a way of dealing with a cognitive dissonance between the optimal care they wanted to give and what they could deliver within the existing constraints, thus, this was a portrayal of their view point rather than untruthful reporting.

A further limitation was the involvement of residents with cognitive impairment. Due to short term memory problems they were sometimes unable to remember when they had been offered choices. Observations filled this void and these residents were able to report how they felt about making decisions and what was of importance to them. All participants told their stories from their own perspective and this varied. Although this did provide challenges in the analysis of the data it also provided a fuller and richer picture of life in the Home.

7.8 Conclusion

This chapter has discussed the findings in relation to the literature. It discussed the findings in the light of previous empirical work, argument based literature, policy and theory. In response to the first research question; What decisions are made in care homes?

it began by discussing decision types and their categorisation. It continued with a discussion based on the two central phenomena, resident as decision maker and others deciding for resident. This section considered the answers to the research questions; Who makes the decisions and with what authority and/or responsibility? and. What are the barriers and facilitators for residents to making their own decisions and what factors influence relatives' involvement? Addressing the final research question; To what extent is the policy and public discourse of values in decision making reflected in the practice of staff? there follows a section exploring key values in decision making in care homes, namely, autonomy and dignity and whether the discourse on values is reflected in everyday practice. The final two sections focus first on the tension between the autonomy of residents and the need for providing a facility that delivers care for all residents, for the needs of their relatives, the staff and the organisation. The final section is on solidarity and how this could be the value that helps to relieve this tension.

The following chapter concludes the thesis by considering what new knowledge has been generated on decision making in care homes for older people. The implications and recommendations, derived from the findings, for future practice, research, policy and education are included. These recommendations are aimed at improving the wellbeing of residents in the care home, supporting their relatives and making employment in a care a better experience for the staff.

Chapter 8

Conclusion and Recommendations

8.1 Introduction

This chapter concludes the thesis by considering what new knowledge has been generated by this study and the implications for decision making for policy, research, education and practice. It finishes with recommendations for enhancing the wellbeing of care home residents their relatives and friends as well as staff.

This study focused on decision making in care homes for older people from the perspective of residents, their relatives and staff using multiple methods of data collection. Care home residents, due to their dependence on others, are potentially vulnerable and empowerment and appropriate decision making by others can enhance their quality of life. With this in mind, I aimed to explore; the process and influences on everyday and significant decision making on older people living in care homes. I aimed to do this in the context of current policy and discourse, and to assess the implications for practice. I considered decision making in the context of values, particularly autonomy and dignity as these dominate the discourse on decision making in the care of older people.

The salient findings were identified using the two phenomena which have been outlined in the previous chapters. The findings are detailed below under the corresponding research questions and a discussion of their implications and resulting recommendations follow.

1. What decisions are made in care homes?

The key findings were;

- Three types of decisions, everyday, infrequent and advance decisions were observed in the care home setting.
- Advanced care planning is advocated but not always practiced by staff and other groups are ambivalent about its importance and utility.

2. Who makes the decisions and with what authority and/or responsibility?

3. What are the barriers and facilitators for residents to making their own decisions and what factors influence relatives' involvement?

The key findings were;

- Tension existed between respecting individual preferences and meeting the needs of residents as a group, relatives, staff and the organisation.
- Relatives were not fully engaged in decision making in care homes.
- Residents' preferences in group home settings were not always respected.

4. *To what extent is the policy and public discourse of values for care reflected in the practice of staff?*

The key findings were;

- There was a lack of awareness amongst staff of law and policy, notably, mental capacity went unrecognised.
- Staff appeared neither to recognise the ethical dilemmas in their work nor did they use the language of ethical principles or values.

8:2 Three types of decisions.

None of the empirical studies included in the literature review explicitly considered the type of decisions made in care homes. Three types were identified, the everyday, infrequent and advance decisions. Priorities differed between residents, their relatives and staff with residents most frequently considering everyday decisions as most important to them, relatives and staff put infrequent decisions as their priority. Relatives often considered financial issues and where the resident lived as important, the staff, particularly registered nurses, were concerned about safety and health issues. Senior staff thought advance decisions were important but most residents and their relatives did not agree, with many not wanting to face end of life issues in advance. As suggested in the National Gold Standards Framework (2010), Froggatt et al (2009) and Froggatt and Payne (2006) considered that advance care planning can improve end of life care. As residents were sometimes found to be hospitalised or given inappropriate treatment when advance decisions were absent, this was confirmed by this study.

8.3 Advance decisions

Although advance decisions were considered important by senior staff in the Home most residents and relatives did not concur.

Few relatives had talked to residents about what they would want in the event of future illness. Nevertheless, many believed they knew what a resident would want based on a shared history. With reluctance to address the issues early, many residents had cognitive impairment at the time decisions needed to be made and consequently lacked the capacity to be involved in decisions with significant consequences, a finding also from Froggatt et al (2009). The relationship between the Gold Standard Framework (2010) which staff state they apply, differed from the practice observed in this study. This is likely to be true in other care homes as the CQC (2012b) noted that even when homes had policies and procedures in place these were not always put into practice, they use the example of Do Not Attempt Resuscitation policies. Froggatt et al (2009) found managers of care homes, who had a commitment to advance care planning, noted barriers to the process. That study lacked the involvement of other actors in the home and relied on self report but this still adds weight to the possible generalisation of this study's findings. Thus, new and innovative ways of engaging staff and relatives in this type of discussion must be sought if the advantages of advance care planning are to be realised.

8.4 Residents' preferences not always respected.

Despite a generally caring workforce who report their view that offering residents choices was important to their well-being and their belief that almost all residents could make at least some decisions, the preferences of residents in this group home setting were not always respected. This finding concurred with some of the empirical literature (Dunworth and Kirwan 2009; Cook 2008; Train et al 2005; Scott, Välimäki, Leino-Kilpi et al 2003) suggesting that it is similar in other homes. However, I assert that this is more complex than previously suggested, requiring an understanding of both resident and staff characteristics and organisational factors.

In this study it was clear that residents varied considerably in their desire for making decisions and their satisfaction with the choices offered. Whilst some residents fiercely held on to control, others showed a more passive acceptance of care as others prescribed it. The findings from previous studies were mixed with some finding acceptance of control (Hughes and Goldie 2009; Scott, Välimäki, Leino-Kilpi et al 2003) whilst others found residents dissatisfied with their lack of choices (Train et al 2005; Tester et al 2004).

I have argued that residents' characteristics are significant in influencing how much involvement they perceived, wanted and actually had in decision making. Physical and cognitive ability were significant factors influencing residents' ability to make decisions. Capacity is addressed in section 8.7 in this chapter. Life history affected both expectations and perceptions of the choices they were able to make. This, as well as personality, affected the residents' level of assertiveness and consequently their decision making. Some of the empirical studies (Cook 2008; Tester et al 2004) mentioned issues relating to residents' characteristics in the decision making process. In addition, the findings from this study suggest that 'learned helplessness' may have played a part in residents not actively trying to control decision making about their lives. This has not been discussed before in the empirical literature.

Staff characteristics were also found to act as facilitators or barriers to residents' involvement in decision making. Staff's communication skills were seen, in this study, to be particularly significant. With good communication, staff were able to assess residents' preferences but the quality of staff's communication skills varied. Many of the staff did not have English as their first language. This was considered a problem by some residents. Neither language nor cultural differences have been discussed in other studies.

The power differential and role demarcation between care workers and registered nurses led to a lack of recognition by care workers of their own role in decision making in what was a hierarchical organisation. Although some previous studies (e.g. Wheeler and Oyebode 2010) noted the demarcation of roles and suggested this was not ideal in the provision of care, there was no discussion on whether this impacted on residents' empowerment to take control and make decisions. Some demarcation is necessary as registered nurses have different skills and are more accountable, to their profession, management, the public as well as those in their care.

Decisions about hospitalisation and medical treatment were commonly made by staff and doctors. Sometimes these were made because a resident lacked capacity or they would sometimes persuade a resident to have treatment they considered appropriate, at times involving relatives to assist with persuasion. However, when residents complied, often decisions were made without consulting relatives first.

The two most significant factors that resulted in restrictions on residents' choices were:

- Staff's fear of the risk of harm and subsequent defensive practice and
- Staff numbers

Concern about risk of harm and the need to balance risk with residents' rights to make their own decisions was not a new finding (Train et al 2005, Boyle 2004, Dunworth and Kirwan 2009, Hughes and Goldie 2009). In this study, there was evidence of defensive practice with residents' decisions often being overridden in order to provide safe care and keep the home running smoothly. Staff's concern was that they should act in a resident's best interests, ensuring their physical wellbeing and safety, with little evidence that they recognised there were other elements to residents' wellbeing, such as the psychological and social. With evidence from previous studies and the characteristics of the Home being similar to many others, this risk averse practice is likely to be prevalent in many care homes.

Although St Bernadette's Service Users' Guide declared a philosophy of responsible risk taking, fear of risk largely prevented this materialising. There is a divide between the literature on positive risk taking (see chapter 7, section 7.2.3.2) and the Home's philosophy and the practice.

At times this study found that staffing levels acted as a barrier for residents deciding, this has been identified by other studies, (Boyle 2010; Wheeler and Oyeboode 2010; Froggatt et al 2009; Hughes and Goldie 2009) suggesting that this is a common problem. Staff numbers were often perceived to be low by both residents and their relatives although this was not acknowledged by staff. A conclusion from this study was that the staffing levels made it difficult to provide the minimum standards laid down in legislation. Staffing levels were found to restrict residents' choices and, at times, were too low to deliver the CQC (2012a) minimum standards to provide for residents' welfare needs in addition to necessary physical care.

8.5 Relatives' engagement in decision making

Relatives' involvement, in this study, often had a positive impact on residents' decision making as they advocated and supported both decision making and decision enactment. They could also provide a life history and help staff understand residents' values through input into care planning. There was diversity between the level of involvement relatives

wanted leading to more or less satisfaction. Relatives' expectations and assertiveness influenced the nature of their involvement and thus, how they influenced residents' opportunities to make choices. It was observed in this study that the relatives who were most assertive in directing care were younger and educated professionals.

Many relatives experienced distress regarding the residents' admission to a care home and increasing frailty (also found in Clarence-Smith 2009 and Jones and Manthorpe 2002). There was an apparent lack of empathy from staff (see chapter 6, 6.5.1.2) which concurred with Train et al (2005). As relative involvement was shown to be an asset, more empathy may have added to their engagement. It was noted that relatives' involvement was not fully exploited. The concept of solidarity could prove useful, with staff and relatives working together towards a common goal and providing mutual support which in turn would benefit residents. All care home communities consist of residents, their relatives and staff and solidarity provides the rationale to consider the wellbeing of all.

8.6 Tension between respecting individual preferences and meeting the needs of others.

There was a tension between the desire to provide choice and make decisions focusing on each resident's individual needs and the needs of other actors and the organisation. Relatives and staff although wanting all residents to receive appropriate care and treatment also had their own needs. Relatives often needed psychological support and practical advice. Staff needed support and their efforts to be validated to enable them to gain satisfaction from their work and to avoid dissonance between the care they believed they should be delivering and what in practice they could deliver. The Home was a business whose aim was to make a profit. Thus, it needed to be managed efficiently and cost effectively and to retain a good reputation.

There was a dissonance between some of what staff reported in relation to providing choice to residents. Staff did not recognise the conflict between their espoused view that residents should make their own decisions and their practice. Dunworth and Kirwan (2009) also found that, although staff considered a deontological approach, offering autonomy, in practice they followed a more pragmatic approach where provision of safe care and avoidance of risk as well as routines and universalised systems all overrode a resident's autonomy.

Due to the nature of communal living, some restrictions existed. Staff time was finite (see section 8.4 above) and with this in mind residents would comply with the routine even if it did not match their preferences and staff often took compliance as their authority to make decisions on residents' behalf. Although it has been noted that many of the worst elements of total institution (Goffman 1961, see section chapter 7. 7.2.3.2) are a thing of the past, some of what Goffman (1961) described was still in existence. Older people's existing roles disappeared and much self determination could be lost. As staff attempted to provide care and safety, residents' emotional, psychological and social wellbeing could be overridden. The Home was isolated from the community at large with few residents going outside. This appears to be a common situation with few care home residents being part of the community in which they live.

Staff lacked recognition of the dissonance between their expressed belief that residents should be allowed to make their own decisions and their practice. They aimed to provide what was considered appropriate care and to minimise the risk of harm. This dissonance was not identified in previous studies. This is an important issue and raises the question of whether greater awareness of this dissonance would change practice.

8.7 Staff lack awareness of law and policy

Staff generally appeared to lack knowledge about the law and policy affecting care home practice, both local and national.

The principles of the Mental Capacity Act (MCA) (2005), especially in relation to capacity, did not appear to have penetrated staff practice in this study and that is likely to be true of similar groups of staff in care homes (see the findings of Manthorpe et al 2011). It was an important finding that was not evident in studies included in the review (chapter 2), that staff lacked understanding and recognition of residents' capacity. The study by Manthorpe et al (2011) did have similar findings but was conducted in the year following implementation of the Act, while this study has offered an insight almost five years after the Act came into force. The concept of capacity was little discussed by participating staff and there was almost no evidence that it was taken into account when considering whether a resident should be allowed to take a risk of their choosing. Further, the concept was not

considered when basic care was refused by a resident, with reports of care workers' view that providing essential care against the wishes of a resident could be construed as abuse.

Involvement of relatives, particularly in care planning, was considered to be universally appropriate by staff, disregarding residents' confidentiality if they had capacity. In practice few relatives reported involvement. The CQC (2012b) found that a lack of person-focused care planning in some homes and many failing to take into account relatives' views. In this study most residents and relatives agreed that the relative would be the right person to decide if the resident were unable (none explicitly mentioned capacity) and most residents were pleased to have relative involvement while they still had capacity. However, it was inappropriate of staff to assume a resident wanted a relative involved without first asking. This lack of recognition of the importance of mental capacity could breach confidentiality. Capacity is a significant issue in care homes where many residents have cognitive impairment which may be affecting their capacity to make certain decisions. This has identified a gap in staff's knowledge and education which needs to be bridged.

The lack of legal knowledge was seen as some clinically inappropriate decisions, hospital admissions, resuscitation and enteral feeding were made at the request of residents or relatives. Where residents lacked capacity this would breach the MCA (2005) if the decision was not in the residents' best interests. If a resident had capacity and requested treatment there is no legal requirement to provide it if it were not clinically appropriate (see the discussion in chapter 7, 7.2.3.2).

All registered nurses in the Home had been educated outside the UK and most of the care workers, including all of those who were interviewed, were not born in the UK. Thus, their knowledge of the law may have been more limited than had they been educated in the UK and this requires further investigation.

There was also only one brief mention by staff of the MCA (2005), Deprivation of Liberty Safeguards despite their relevance in care home practice. The defensive practice witnessed, may have been partly due to an ignorance of the law. The Human Rights Act (1998) was mentioned by only one participant and she was unable to articulate how it influenced her practice and decision making.

Staff's poor knowledge of the law meant that this was an area where practice was not appropriately guided.

8.8 Staff do not appear to recognise ethical dilemmas or use the language of ethical principles or values.

This study found that staff appeared generally unaware of the ethical implications of their practice. This was also identified by Dunworth and Kirwin (2009). This study found that both staff and relatives did not have the vocabulary to discuss the ethical issues embedded in life in a care home. Participants did not use the terms autonomy and dignity despite the large literature on the topics. Their discourse was on the practical and concrete rather than on the philosophy of the values and concepts underpinning actions.

Nordenfelt's (2009) dignity of identity did appear relevant to this study's findings. However, "identity work" and "dignity work" (Öhlander 2009, see chapter 7, 7.3.4.1) by residents and themselves was not recognised by staff. With consideration of continuity of personhood, (see Dworkin 1993), this can be relevant to individuals, even in the later stages of dementia.

Solidarity is a concept appearing more frequently in bioethical literature recently and has significance to life in care homes. It is a concept that like autonomy and dignity is poorly defined. However, its less individualistic approach can be more appropriate to the communal life in a care home than autonomy and more specific than dignity. Staff are experiencing a dissonance between the desire to respect autonomy and maximise residents' choices which they believe they should be providing and what they are able to deliver. Care workers were delivering care prescribed by registered nurses and had received training that encouraged tailoring care to the individual residents and their needs and wishes. This required them to make decisions in their everyday work which they often did not recognise. They lacked recognition from others of the importance of their role which could discourage them from taking a place as part of the team which could contribute to the provision of the best quality care. Registered nurses were providing the leadership on decisions about everyday care as well as issues relating to health care and treatment. They too had difficulty recognising the difference between the need to provide good care and treatment and other ethical dimensions of their work. Registered nurses had the NMC code to guide their practice. Scotland and Wales have, in 2011, both produced

codes of conduct for health care support workers in an employer led regulation model (Hand 2012). Northern Ireland has a voluntary register but this is not mandatory (Royal College of Nurses (RCN) 2012b). Now the Health and Social Care Act 2012 has received royal assent, the establishment of a code of conduct and national minimum training standards for health care support workers and the implementation of a voluntary register is planned in England. The RCN (2012b) continues to believe that all those working in health and social care with vulnerable people should be governed by statutory regulation, however the DoH (2011) Command Paper did not consider that there was a need to regulate all those who work in the sector as they consider other safeguards to be sufficient. This leaves the unregulated work force without a clear understanding of their role and unaccountable for their actions. Regulation could give care workers more status and, through accountability, encourage reflection on practice. This could encourage better team work, nurses do have a different role due to their education and training, but the value of the care worker's role should also be recognised.

Solidarity could help staff to act as a more coherent team and to reduce the dissonance staff experience while still providing a framework for good care. This study has demonstrated the current discourse is little recognised and not acted upon. Thus, new and imaginative ways need to be employed to engage care home staff who have often received little training and many of whom are not native English speakers and may have limited knowledge of British culture.

8.9 Recommendations and implications

8.9.1 Recommendations for policy in relation to decision making

1. Policy documents at all levels should use clear operational definitions of the words 'autonomy' and 'dignity' or provide value based statements in place of these terms.

The purpose of policy, whether national or local, is to provide the impetus to improve practice. As is said in the forward to the Delivering Dignity report, "The last thing we want is to produce a report that generates more noise than practical action" (NHS Confederation 2012 p2). Based on the findings of this study, it appears that this is often the case with policy documents at all levels. It has been noted that policy discourse is not penetrating everyday staff practice in particular in relation to supporting autonomy through responsible risk taking and empowering residents to take control of as much of

their life as they wish and are able. I suggest that discourse in policy and guidelines would do better to concentrate on more specific value based statements such as;

- offering and allowing residents to make choices;
- knowing and respecting the person and;
- treating them as an individual and providing person centred care.

This is often what authors appear to mean when they use the term autonomy, and as evidenced by this study, staff working closely with residents do not use the term ‘autonomy’. I suggest that policy, public and local, regarding health and social care which recommends provision of choice for residents of care homes, avoid using the term autonomy without definition. Autonomy is much used in policy from the Department of Health (e.g.2010c) and the MCA code of practice (2007) for example. This is a small scale study, any generalisation has to be mooted with caution (see chapter 7,7.6), but as the Home was selected for its similar characteristics to large numbers of other homes in the area, there is no reason to expect that findings would not be similar in other homes. Therefore, I suggest that specific statements incorporating choice, respect and individuality would be more appropriate to this workforce.

The word dignity was not used by participants. It appears, with the necessary caution of generalising from a case study, that as with autonomy, the discourse is not influencing practice. The use of the term dignity in policy relating to choice and decision making is equally ambiguous. It has been argued, most notably by Macklin (2003), that dignity adds nothing to the discourse on care. Although I would disagree with this in a general sense, using the word without a definition in a policy document does appear to add very little. Either, the concept needs definition each time it is used, or the elements of dignity applicable to the given policy be listed (see National Pensioners Convention 2012).

2. Solidarity, if defined, would be an appropriate term to use in policy to incorporate the values needed in a care home for older people.

It would also be helpful if policy moved closer to the concept of solidarity where all actors are considered and mutuality can be recognised. Solidarity could promote collaboration in decision making and empower, residents, relatives and staff. Person centred care (McCormack and McCance 2010 p1) includes some elements of solidarity such as “mutual trust and understanding” and Kitwood (1997) recognised that an organisation

needed to respect staff. However, solidarity can take the idea that all those involved in the home are 'in it together'. Residents their relatives and staff all need support and at least part of this can be obtained from other people in the home. However, caution is needed to avoid replacing difficult to define concepts with another, solidarity, which is equally difficult to define. The relevance of other values need consideration to establish whether autonomy, dignity and solidarity can provide an adequate ethical framework for decision making in care homes. Beneficence and nonmaleficence are important and may help to establish best interests where a resident lacks capacity. However, if a person who lacks capacity is treated with dignity they would also be treated with beneficence and nonmaleficence. Best interests can best be established by involving all those who are involved in their lives and this can embrace the value of solidarity. Solidarity would also incorporate justice as it considers all those who live, work and visit a care home. Autonomy can apply to a resident who under this value should be allowed to make the choices they want and are able to. The staff, require a level of autonomy to ensure they can provide appropriate ethical care. In relation to decision making the three specified values may well be sufficient to guide practice.

3. Statutory regulation of all care workers is recommended.

In concordance with the views of the RCN (2012b), I believe that statutory regulation of care workers would benefit care workers and those in their care. This study found that care workers were disempowered and therefore their contribution to care home life was limited. Their status, accountability and training would be increased if they were regulated, allowing them to contribute more fully and lead to better care for residents.

4. There is a need for national guidance on staff numbers and skill mix in UK care homes for older people.

As discussed already staff numbers can affect residents' opportunities to have choices. The RCN (2012 p7) called for "national guidance on staffing levels and ratios for care homes." while the Northern Ireland Human Rights Commission (2012 p71-2) recommended "that staffing levels should be raised progressively over time to ensure the delivery of more than minimum essential levels of care." The findings from this study support the appropriateness of these recommendations.

8.9.2 Recommendations for future research

1. Research should be conducted to establish whether nurses educated outside the UK have sufficient knowledge of UK policy and law to guide their practice and whether this differs from the level of knowledge of their UK educated colleagues.

Even if policy, whether from the level of the Department of Health or in an individual care home, were made clear and specific it is not useful if the people involved in care homes are unaware of them. This study showed that nurses lacked knowledge of law and policy. As all the nurses in this study were educated outside the UK, future research should assess whether there is a difference in this type of knowledge between UK educated nurses and those from other countries. There is also the need to establish what knowledge staff educated in the UK have of law and policy to identify the gaps so these can also be filled.

2. There is a need for research to explore whether communication problems affect care where non-native English speakers are caring for English speaking residents in care homes.

The communication skills of staff was found in this study to be important to residents affecting their ability to understand residents' preferences (see chapter 5, 5.4.4.3 and chapter 7, 7.2.3.4). As many of the staff did not have English as their first language it is necessary to explore whether this is affecting communication and thus, residents ability to make choices. As Hussein, Manthorpe and Stevens (2011) reported that 68% of care workers in London are non-British born this is likely to be a widespread issue.

3. Research is needed to establish whether raising ethical awareness improves practice and how this would affect staff's stress level and job satisfaction.

The findings of this study showed a lack of awareness of ethical issues amongst staff (see chapter 6,6.4). It would take further research to discover whether raising the awareness of the ethical issues would improve practice. This would need a cautious approach as oblivion to these issues may be a coping strategy for many staff to avoid uncomfortable dissonance. Attitudes and behaviour before and after the intervention would be measured to assess whether there was an improvement in practice, as well as how staff stress and job satisfaction were affected.

4. Exploration of whether learned helplessness is a common problem in care homes for older people should be conducted.

This study has found that learned helplessness is a likely explanation for residents' reluctance to make decisions on their own behalf (chapter 7, 7.2.3.1). I argue that this theory is worth further investigation.

5. There should be exploration of whether empowerment of staff and team building would lead to staff better supporting resident choice.

As was noted in the previous chapter (7.3.2.2) staff often lacked autonomy. Power differentials led to the skills and contribution, particularly of care workers, to be underutilised. Action research, where empowerment would be put into practice to explore its effects would be appropriate.

6. Action research to enable staff to better understand the perspectives of relatives should be enacted to test whether this enables responsible risk taking for residents.

Many relatives in this study were found to be experiencing or had experienced psychological distress regarding the placement of the resident in a care home and their other caring responsibilities (see chapter 5, 5.4.3 and chapter 6, 6.5). The staff did not appear to recognise this. Whether care home staff who are more empathetic could engage relatives to enable better, more individualised care is currently unknown. The characteristics of relatives is also relevant with this study finding younger more educated relative more assertive, whether this is the case in other care homes is worthy of investigation. This, along with the consideration of whether more understanding would enable staff to discuss responsible risk taking more successfully than staff who are less empathetic needs further research.

7. Research should investigate the appropriateness and utility of asking all residents, and where appropriate their relatives about advance planning for end of life care.

Despite the Home's professed use of the Gold Standards Framework (2012), advance care planning was little in evidence. As many residents and relatives did not consider advance

planning to be important (see chapter 5, 5.5) it is necessary to examine whether they wish to discuss these issues, to ensure they are allowed the level of involvement they want. Where they would prefer not to discuss the issues, staff and doctors would consider the most clinically appropriate course of action to avoid inappropriate treatment and hospitalisation. Staff also need education to raise awareness that there is no obligation to offer clinically inappropriate treatment. As the GMC (2010) stated, this has the potential to distress both the patient and the professional.

8. Staff should be encouraged to become active partners in research in the care homes in which they work.

Users of health and social care services and those who care for them have been encouraged to become involved in research in recent years as they are the ‘experts’ (see Involve 2012). This has helped to gain their perspective and to empower them. However, research in care homes also needs the engagement of the staff. Research, policy and practice initiatives dictating how care home staff should act are in abundance. Only if staff are fully engaged will their practice change. Thus, I recommend that researchers collaborate with staff to design, collect data, analyse and disseminate research. This should include staff at all levels as care workers can be as important to the resident experience as managers. Staff often feel criticised in their everyday practice, so sensitive research methods such as the appreciative enquiry model (Cooperrider, Whitney and Stavros 2008) would be appropriate to involve staff in deciding how they could improve their practice.

8.9.3 Recommendations for education

1. Staff should receive education on UK policy and law relating to care home practice. If found to be necessary (see 8.9.2 recommendation 1 above), staff educated outside the UK should be targeted for such an education programme.

There needs to be knowledge of the law and legal concepts to guide practice. The most notable issue where this was found lacking in this study was in relation to capacity (see chapter 7, 7.3.2.2 and chapter 8, 8.7). It might be expected that registered nurses would have knowledge of law, ethics and policy, however, none in this Home had received their

nursing education in the UK. If there is a difference it would be appropriate to test the knowledge of nurses registering to practice in the UK and to provide training.

2. Staff should receive ongoing education on the ethical dimensions of their practice.

Staff demonstrated in this study that they often did not recognise the ethical issues and implications of their practice (see chapter 6, 6.4) . Ethical dilemmas in working with potentially vulnerable people in a residential setting identified in this study were multifarious. The most significant finding was the tension between a desire to maximise residents' choices and decision making while managing risk and the other needs of the Home and the actors within. This would need a cautious approach as oblivion to these issues may be a coping strategy for many staff to avoid uncomfortable dissonance. I recommend that an educational intervention should be implemented to help staff reflect on the ethical components of their practice to assist them to be guided by policy and law. With any education intervention desirable changes must be sustained. The clinical leaders in the care home would need to maintain use of ethical and legal language and discussion of ethical and legal issues to ensure any improvement in care continued. This could readily be incorporated into everyday conversations in the care home, at hand over or when planning care for example. With little effort, time or resources any advantages of the learning intervention could be sustained.

8.9.4 Recommendations for practice

1. Responsible risk taking should be promoted in care homes for older people.

In response to the findings that residents' choices and decisions are not always respected and that this is frequently due to fear of risk of harm, responsible risk taking, when it is desired by the resident, needs promotion. It has been established that wellbeing can be enhanced through an element of risk taking if this is what a resident wants (see discussion in chapter 7, 7.2.3.2). This might best be achieved by establishing where responsible risk taking is already practiced and to explore what are the factors that make this practice possible so it can be widely disseminated through the care home sector.

2. With residents' consent where possible, relatives should be encouraged to take a more active role in care home life, sharing their knowledge of residents with staff and planning care and treatment.

It was noted in this study that relatives' involvement was not exploited to the full and this appeared to be another reason staff were reluctant to allow residents to take risks (see chapter 6, 6.2 and 6.5). Ways relatives can be more involved in residents' care to promote responsible risk taking needs consideration. The employment of strategies such as meetings for residents, their relatives and friends and staff would improve communication, involve all interested parties and minimise the effects of routines and systems governing an institution.

8.10 Conclusion

This study has used grounded theory methodology within a case study framework to explore the perspectives of residents, their friends and relatives and staff in a care home. By including these different groups of participants, together with people with dementia, using interviews, observation, informal conversations and viewing documentation and immersing myself in the Home for a year, it developed a broad and in depth picture of life in the Home.

Although the promotion of choice and autonomy and these elements of dignity are evident in policy and literature, practice often did not match the discourse. There was a lack of knowledge amongst staff in relation to policy and the law and particularly around mental capacity. There was also a lack of understanding and vocabulary of ethics amongst all participating groups. It was found that staff's fear of risk and staff numbers were two of the main elements in reducing residents' opportunities to make decisions and choices. A tension existed between the values of respecting residents' choices and keeping the resident safe while ensuring the other actors' needs were incorporated and the profit making business that was the Home could continue to run smoothly.

I have made recommendations for policy including defining autonomy and dignity when they are used in policies or using the working definitions rather than the terms. The need for solidarity to be adopted as an espoused value has been identified as appropriate as one of the ways of relieving the tension described above. As staffing levels have been shown

to have a significant impact on resident's choice and decisions and thus on their welfare. staffing levels need re-examination.

I made several recommendations for future research and education. Whether the knowledge gap relating to policy and law only applies to non-UK educated nurses or is universal requires further research. Once the extent of the gap is established an educational programme is needed with assessment as to how this changes staff practices. Education is also needed on ethical principles with sensitivity to how this might affect staff and their job satisfaction.

I recommended that relatives need to be optimally engaged in the care of residents and assisting in understanding the advantages of responsible risk taking. One barrier may be the lack of empathy by staff towards relatives but this needs further exploration. If this is shown to be the case a short awareness programme could be implemented with relatives voicing their experiences to care home staff. Any resulting behavioural change would require evaluation.

In addition to the expansion of service user and carer involvement in research and education, I recommended that staff must be encouraged to become fully involved in all elements of care home research.

The findings have implications for practice. Policy, the law and discourse on ethics are little known and poorly understood by staff and have had little impact on practice in relation to choice and decision making in care homes. Further, relatives perspectives are little understood by staff and the benefits they could bring to resident care was poorly exploited.

I suggest that all these issues can be addressed through mentoring within a care home and reciprocal sharing of good practice between homes. The staff need to be constantly involved and leading change towards better practice themselves. Positive methods (e.g. appreciative enquiry) of exploring the ways practice could be improved should be employed. This way staff's good practice would be recognised, encouraging them to drive towards the best.

I started this project with concern about the potentially vulnerable residents of care homes and their rights and welfare. The outcome has been that the study showed that there are many ways that practice could improve to empower residents and improve their quality of life. However, I have also come to realise that the other actors in the home, the staff and relatives and friends also have needs that cannot be ignored. Further, the 'organisation' needs to flourish for the benefit of all. This causes some tension as different priorities compete. However, it is my belief that if the care home is seen as a community and all actors are valued and reciprocally supported under the value of solidarity, much of this tension would be relieved. The practice of solidarity could lead to a care home being not just a better place to live, but also a better place to work and visit.

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Appendices

Appendix A: Table A. Review of Qualitative Studies

| | Bowers et al (2009) | Boyle (2004) | Clarence-Smith (2009) | Cook (2008) | Dunworth & Kirwan (2009) | Froggatt & Payne (2006) | Froggatt et al (2009) | Hughes & Goldie (2009) | Jones & Manthorpe (2002) | Joseph Rowntree Foundation (2009) | Tak-Ying Shiu (2001) | Tester et al (2004) | Train et al (2005) | Wheeler & Oyeboode (2010) | Winterburn (2009) |
|-----------------------------------------------------|---------------------|-------------------------------------------------|----------------------------|-------------|--------------------------|-------------------------|-----------------------|------------------------|----------------------------|-----------------------------------|----------------------|---------------------|--------------------|---------------------------|-------------------|
| <i>Clear research questions?</i> | √ | X general aims could be extracted from the text | X explicit aims identified | √ | X aims changed post hoc | √ | √ | √ | X explicit aims identified | √ | √ | √ | X aims specified | X aims specified | √ |
| <i>Questions suited to qualitative enquiry?</i> | √ | √ | √ | √ | √ | √ | √ | √ | √ | √ | √ | √ | √ | √ | √ |
| <i>Clearly described sampling?</i> | X | √ | X | X | Limited | √ | √ | √ | √ | X | X | X | √ | X | √ |
| <i>Clearly described data collection?</i> | X | √ | √ | X | √ | √ | √ | √ | X | X | X | √ | √ | Limited information | √ |
| <i>Clearly described analysis?</i> | X | X | Limited information | X | X | √ | √ | √ | X | X | X | X | √ | Limited information | X |
| <i>Sampling appropriate to the question?</i> | unknown | √ | unknown | unknown | unknown | √ | √ | √ | Some limitations # | unknown | unknown | unknown | Some limitations # | unknown | X |
| <i>Data collection appropriate to the question?</i> | √ | √ | √ | √ | √ | √ | √ | √ | √ | √ | √ | √ | √ | √ | √ |
| <i>Analysis appropriate to the question?</i> | unknown | unknown | √ | unknown | √ | √ | √ | √ | unknown | unknown | unknown | unknown | √ | unknown | unknown |
| <i>Claims supported by</i> | X | √ | √ | √ | √ | √ | √ | √ | Limited evidence. | Limited evidence. | X | X | √ | √ | X |

| | | | | | | | | | | | | | | | |
|--------------------------------------------------------|--------------------------------------------------------------------------|---|---------|--------------------------------------------------------------------------|---|---|---|---|-----------------------------------------------------------------|----------------------------------------------------------------------|---------|----------------------------------------------------------------------|---|---------|---------|
| <i>evidence?</i> | | | | | | | | | | | | | | | |
| <i>Data interpretation and conclusions integrated?</i> | X | √ | √ | √ | √ | √ | √ | √ | Limited integration | √ | X | X | √ | √ | X |
| <i>Useful contribution?</i> | √ (findings treated with caution as insufficient information on method.) | √ | √ | √ (findings treated with caution as insufficient information on method.) | √ | √ | √ | √ | √ (findings treated with caution, lack of supporting evidence.) | √ (findings treated with caution due to lack of detail about study.) | unknown | √ (findings treated with caution due to lack of detail about study.) | √ | √ | unknown |
| <i>Ethical?*</i> | unknown | √ | unknown | unknown | √ | √ | √ | √ | √ | unknown | unknown | √ | √ | unknown | √ |

From Dixon-Woods et al (2004)

*'Ethical' has been added as most of these studies include potentially vulnerable people and the quality of studies cannot be considers outside of the ethical context.

Limitations identified by the authors.

Appendix B: Table B. Review of Survey Studies

| | Boyle (2004) | Dunworth and Kirwan (2009) | Froggatt & Payne (2006) | Froggatt et al (2009) | Scott, Välimäki, Leino-Kilpi et al (2003) |
|----------------------------------------------|------------------------------------------------|-------------------------------------------------------------------------------|--------------------------|--------------------------|------------------------------------------------------------------------------------------|
| Survey designed to answer the question? | X | X The question is not explicit. | X | √ | √ |
| Can it answer the question? | √ | X See above | With some limitations * | √ | √ |
| Clearly described population? | √ | X limited information on participants. | √ | X Lack of detail | √ |
| Response rate? | Reported but low (19% of eligible residents) * | √ (71.5%) | Reported but low (33%) * | Reported but low (42%) * | X |
| Representative sample? | X * | All staff surveyed but it is uncertain whether the homes were representative. | Some concerns * | Some concerns * | X * |
| Objective and reliable measures? | √ | X Vignettes used and both qualitative and quantitative data collected. | Unknown * | Unknown | Cronbach alpha coefficient values discussed * |
| Most appropriate measures for this question? | √ | Partially | Partially | √ | √ |
| Subgroups using the same methods? | √ | √ | N/A | N/A | X Different methods were needed for residents and staff |
| Survey method described? | √ | √ | √ | √ | √ |
| Method avoids bias? | √ | √ | √ | √ | Self report from staff may have led to reporting what ought to be rather than what is. * |
| Large enough sample? | Residential sample √ Household sample X * | No statistical tests reported, so uncertain* | √ | √ | Relatively small sample * |
| Enough description of data? | √ | √ | √ | √ | √ |
| Evidence of multiple statistical testing? | √ | X No statistical tests reported | Largely descriptive | √ | √ |

| | | | | | |
|-----------------------------------------------------------------|---|----------------------------------------------------------|---------------------|---|--------------------|
| Evidence of minimal use of a large amount of post hoc analysis? | √ | X Reported different findings from the original question | √ | √ | √ |
| Appropriate statistical analysis? | √ | X No statistical tests reported | √ | √ | √ |
| Avoidance of other bias? | √ | Risk of reporting inaccuracy | Some risk of bias * | √ | Some risk of bias* |

Points taken from Petticrew and Roberts (2006) adapted from Crombie (1996)

*Limitations identified by the author

Appendix C: Table C. Review of Experimental Study

| | |
|--------------------------|----------------------------------|
| | Knight, Haslam and Haslam (2010) |
| Selection Bias | Moderate |
| Design | Moderate |
| Confounders | Moderate |
| Blinding | Weak |
| Data Collection Methods | Moderate |
| Withdrawals and Dropouts | Strong |
| Global Rating | Moderate |

From Thomas H (2003)

Appendix D: Table D. Included studies

*These limitations are identified by the authors.

| Reference | Aim/Question | Methods & Participants | Findings | Quality and Limitations |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Boyle G (2004) Facilitating choice and control for older people in longterm care <i>Health and Social Care in the Community</i> 12(3) 212-220 | The main aim was to compare residents in institutions with those in private households, on their perceived autonomy in relation to the importance they placed on having choices. | Structured interviews incorporating standardised measure of quality of life & a measure of perceived choice. 215 residents in 45 care homes & 44 older people receiving domiciliary care in Northern Ireland | People had more choice and control in an institution than when receiving domiciliary care. When choice was restricted, participants reported that such choice was unimportant. Some perceived high degrees of freedom others were satisfied to accept the constraints put upon them, there were others who found constraints on their decisional autonomy confining and frustrating. | As the author indicates autonomy is not absolute so other than relatively it is hard to draw conclusions.* The measure of perceived choice had been used before in the 1970s although whether it remains relevant today is not discussed. 58% of homes and 19% of eligible residents took part and this low response rate may have led to bias.* The “conversational aspects” of the interviews have been used and although apparently not systematically analysed provides additional insight. |
| Clarence-Smith B (2009) Healthcare for people with dementia in care homes: family carer experiences <i>Journal of Dementia Care</i> 17 36-38 | To explore the provision of healthcare to people with dementia living in a care home through the experiences of their family carers. | Semi-structured interviews. 16 family carers of people with dementia in 2 care homes in England. | Prior to entry to a care home, carers felt unsupported becoming exhausted so they wanted to hand over all responsibility to the home. This resulted in confusion over who was responsible for medical care especially as nurses were not employed in the homes. Relatives had little understanding of primary health care and lacked involvement. Advance decisions and end of life choices were rarely discussed except in times of crisis. Relatives describe poor care and communication, in the home, from GPs, hospitals and social services. The positive effect of residents and relatives | 5 homes were approached, 2 agreed to be involved and “selected relatives” were approached. It is unclear how the relatives were selected. Only 2 homes and 5 GP practices were included and limited other services* which may not be generalisable. An appropriate method of in-depth interviews was used. An independent researcher systematically coded data according to themes but there is no further information on analysis. This was a short article and only a few quotes were used to support the findings. Although the findings sound credible the brevity of the article makes it difficult to judge the quality of the methods used to reach the conclusions. |

| | | | | |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| | | | being treated with respect, kindness and sensitivity especially at the end of life was noted. | |
| Cook GA (2008) Older people actively reconstruct their life in a care home <i>International Journal of Older People Nursing</i> 3(4) 270-273 | To develop an understanding of what is important from the perspective of residents in care homes. | Narrative interviews 8 Residents in a care home in England | Frail older people reconstructed their life when they moved to a care home to make it meaningful, purposeful and enjoyable. There were 3 types of strategies, resident initiated and implemented, resident initiated but executed by others and negotiation to identify possibilities and ways to achieve this. Where residents needed assistance from others, in some instances their choices were acted upon, in others ignored. In many situations there was no knowledge by staff or relatives of the actions of residents to implement their decisions. | Narrative interviews gave residents the opportunity to speak freely about what was important to them. The method used was appropriate to the study aims. No method section therefore no detailed information on context, sample, sampling, data collection or analysis. 8 residents in four homes, no opportunity to assess whether the experience of residents is due to the home or internal characteristics. Only selected findings are reported. Absence of context makes it difficult for readers to know if it holds relevance to their own area of practice. |
| Dunworth M & Kirwan P (2009) Ethical Decision-Making in Two Care Homes <i>Social Work in Action</i> 21(4) 241-58 | To find whether different values would be apparent in a home run by a nurse and one run by a social worker | Survey using vignettes. 65 staff members in 2 care homes in urban UK. | No difference in the value base between homes was identified. Workers were unaware of the ethical dimensions of their decisions and confuse ethical responsibility with the rules and procedures related to their job. Respondents believed in the importance of respect for autonomy but in practice acted to maintain safety. | The questionnaire was intended to look for differences between values in the 2 homes, none were found. However it elicited information about the values held by staff when making decisions for residents. Neither the participants nor the settings were well described. No statistical data was reported. The method of analysis for qualitative data is not discussed. |
| Froggatt K & Payne S (2006) A survey of end-of-life care in care homes: issues of definition and practice <i>Health and Social Care in the Community</i> 14(4) 341-348 | To describe, profile of care homes in one English county, the demographic characteristics of the residents, the number and nature of deaths in 2003, the resources to undertake end-of-life care (EoLC), managers | Questionnaire survey. 81 care home managers in England. | There was little structured consultation with residents about their end of life (EoL) preferences, with few residents (2.3%) having made advance directives. | The questionnaire was modified from one used in similar populations but it appears there was no pilot. The response rate was 46% so may not be representative.* There was appropriate use of cross tabs and descriptive statistics and content analysis for open question responses and extra comments. The difficulty that a questionnaire could influence managers views of EoL has been considered.* The aims of describing the homes their residents and resources were achieved but the method may have |

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| | understandings of EoLC and their priorities for its development. | | | restricted the depth of data about managers understanding and priorities relating to EoL.* |
| Froggart K, Vaughan S, Bernard C & Wild D (2009) Advance care planning in care homes for older people: an English perspective <i>Palliative Medicine</i> 23 332-338 | To describe current advance care planning in English care homes for older people including, the extent to which advance care planning was undertaken, which advance care planning tools or other decision making processes were in use, managers confidence & knowledge regarding EoL issues & factors influencing advance care planning in care homes. | Questionnaire & semi-structured interviews. 213 questionnaires & 15 semi-structured interviews of care home managers in England. | Advance care planning was recommended by most (89%) of respondents. One third reported less than 25% had completed an advance care plan, one fifth 75% or more. Knowledge of EoL issues led to confidence in having advance care planning leading to managers having more advance care planning discussions. Ascertaining residents' views, willingness, physical, emotional, cognitive and communication abilities were all important. Some residents with dementia were unable to make decisions. Family issues included willingness, availability and family dynamics. Some staff were uncomfortable with issues around death. In the implementation of residents' wishes, resources, support from other professionals (GPs & District Nurses), care setting, (hospitals) were important. Understanding, the same goals between staff, external professionals and relatives were all important. | The questionnaire study allowed a large number of home managers to be included but the response rate was only 42%* although in several respects the care homes participating did appear to be representative of the population. There is limited information on how the questionnaire was developed but care home owners and managers were involved and it was piloted. The authors recognise that questionnaires do not allow respondents to fully explore advance care planning in all its complexity* but this was somewhat mediated by the interviews. The interviews were analysed using the coding template used for the questionnaire and through thematic analysis. In the findings quotes were only used to support other findings so little appears to have been added from the qualitative work. The study did describe advance care planning practice as was its aim. |
| Hughes CM & Goldie R (2009) "I just take what I am given" Adherence and Resident Involvement in Decision Making on Medicines in Nursing Homes for Older People: A Qualitative Survey | To explore in the nursing home environment, adherence to medication, the extent of residents' input into medication decisions and their involvement in the process. | Semi-structured interviews & focus groups. 8 GPs, 17 residents & 9 nurses in Northern Ireland | They found that there was no problem with adherence to medication regimes. Professionals needed to control prescribing and administration of medication to ensure, safety, quality and continuity of care. Residents had little involvement in decisions about their medication but appeared happy to accept this. Professionals accepted that residents | There is clear information on sampling and method. The response rate for care homes was 12.5% for GPs 42% but for nurses it was only 8% while for residents nominated by nurses 89% took part. The low rate of participation suggests that the sample is unlikely to be representative and the characteristics of the care homes have not been discussed in detail. They do not explain their method of analysis other than to mention constant comparison but use quotes |

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| <i>Drugs & Aging</i> 26(6) 505-517 | | | had a right to be involved in decisions but this was not implemented. | to illustrate their findings which illuminates the issues explored. |
| Jones P & Manthorpe J (2002) Setting standards and enhancing choices <i>MCC Building Knowledge for Integrated Care</i> 10(6) 22-27 | To explore how local standards could be developed and how might they fit within any national framework. | Semi-structured interviews, questionnaires & focus groups. 13 residents, 7 friends/relatives, 4 care staff, 4 managers, 15 community dwelling older people (CDOP) in England. | Most considered talking of death and dying important. Residents considered important, privacy, some would like a door key, choice of clothes, carers linked this to dignity. Mixing with residents with dementia could be distressing. On a number of issues residents had different opinions, whether to be checked or left alone if ill & importance of meal times. Diversity between groups & within groups was identified, a need for flexibility was recommended. Carers prioritised nutrition, medication & measurable care standards, staff thought systems & policies more important than residents, although many staff thought these could detract from service to residents. Residents considered relationships with staff & other residents important. CDOP thought there should be facilities to prepare snacks & drinks although they knew little of life in residential care but expressed preferences. | They included people living or working in a local authority home where only a minority of care home residents lived.* Residents and carers were recruited by care managers so may not have been representative* and those with cognitive impairment were not included*. Questionnaires are used but their content is not reported. The study did include a variety of perspectives although with small numbers of participants. |
| Knight C, Haslam SA & Haslam C (2010) In home or at home? How collective decision making in a new care facility enhances social interaction and wellbeing amongst older adults. <i>Aging and Society</i> | To test the hypotheses, encouraging residents to have collective input into design of communal space will; 1.increase identification & interaction with others in the home & their psychological comfort. | Longitudinal experiment. 27 Residents in one care home in England. | Empowering residents by allowing them to make decisions about décor in communal areas resulted in increased identification with staff and fellow residents, enhanced citizenship and improved well-being. They also made more use of communal space. | The 4 hypotheses were appropriately tested using this longitudinal experiment. It is reported that the scales used showed satisfactory reliability but they had not been fully validated and had not previously been used with this type of participants and the scale had been shortened. The observational data appeared to be subjective and not systematically analysed. The comparison of both time and empowered group vs. control provided useful data. Although statistical significance was found to |

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| 30 1393-1418 | 2.enhance citizenship behaviour towards others using the space. 3.enhance quality of life & physical wellbeing. 4. increase use of the space. | | | support the hypotheses, it was in one home with a relatively small number of people so would need scrutiny of the context before generalisability could be assumed*. |
| Scott PA, Välimäki M, Leino-Kilpi H, Dassen T Gascull M Lemonidou C & Arndt M (2003) Autonomy, privacy and informed consent 3: elderly care perspective <i>British Journal of Nursing</i> 12(3) 158-168 | To examine ethical issues in the care of elderly people in longterm care. How are patients' autonomy, privacy and informed consent evidenced in long-stay elderly care facilities from the viewpoint of patients & nurses? Are there differences between the perceptions of nurses and patients? | Self completion questionnaire for staff & structured interviews for residents. 160 staff, 101 residents in 22 care homes or NHS continuing care units in Scotland | Residents were happy with their opportunity to exercise autonomy. There were marked differences between the responses of nurses and those of residents in relation to information giving, decision making and informed consent. | The questionnaire, although not yet validated, was designed from literature and appropriately piloted. This method may have led to the exclusion of more older residents with cognitive impairment than a qualitative method. There is no explanation of how the continuing care units and nursing homes were selected nor the response rate of older people, a convenience sample of nurses was used. How the sample compares with the whole population is unclear. The sample size was relatively small* and the sample may not have been representative*. The statistical analysis appears appropriate and the results have been well discussed reaching understandable conclusions. |
| Tester S, Hubbard G, Downs M, MacDonald C & Murphy J (2004) What does quality of life mean for frail residents? <i>Nursing & Residential Care</i> 6(2) 89-92 | To explore quality of life from the perspective of frail older people living in care homes. | Focus groups, naturalistic observation in care homes, interviews & conversations. 52 Frail residents in Scotland. | They identified 4 main components of quality of life for participants. These were, sense of self, the care environment, relationships and activities | The multi-method approach was appropriate to gain frail older people's understanding of quality of life, and to maximise residents' opportunity to take part, including people's voices that are rarely heard. There is no description of the care homes nor a description of participants so it is difficult for the reader to know whether findings are relevant to their environment. There is no indication of how analysis was conducted or how the findings were reached. |
| Train GH, Nurock SA, Menela M, Kitchen G & Livingston GA (2005) A qualitative study of the | To explore the positive & negative aspects of the experience of family carers, staff & | Semi-structured interviews. 21 Residents, 17 | 5 main themes, privacy, dignity and choice, relationships, activities, physical environment and expectations of the care environment by staff and relatives. | Details of method, sample, context & analysis were reported allowing transparency. There is some evidence that the process was systematic. It was not reported how the 10 homes were selected although |

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| <p>experiences of long-term care for residents with dementia, their relatives and staff</p> <p><i>Aging & Mental Health</i> 9(2) 119-128</p> | <p>people with dementia living in 24 hour long term care settings & the differences between settings.</p> | <p>relatives and 30 staff in 10 homes in England.</p> | <p>Choice and input into care was important to residents and relatives, risk was balanced against residents' choices, individually tailored activities were more useful than group activities.</p> | <p>their diverse characteristics are. Sampling of residents was largely randomised, thus although there were few participants in each of 10 homes, there is likely a representative sample, although the number of potential participants refusing to take part was not reported. The authors consider that some characteristics of the homes refusing access and residents not taking part may have differed from the participants.* Description of the analytical process is limited but there were a considerable number of quotes which link data to findings adding to the study's credibility. The methods enabled discovery of positive & negative aspects of care for residents with dementia, family care givers and staff that were sought. This was a carer led project.</p> |
| <p>Wheeler NL & Oyebode JR (2010) Dementia care 1: person centred approaches help to promote effective communication.</p> <p><i>Nursing Times</i> 106(24) 18-21</p> | <p>To gather opinions and perspectives of care home staff on communication issues.</p> | <p>Focus groups.</p> <p>36 staff, registered nurses, HCA, activity coordinators and managers in 9 homes for people with dementia in England</p> | <p>Staff should empower residents through person centred care. More emphasis should be on relationship building rather than focusing on tasks. Good team work leads to optimal care and there should be recognition of families' role in providing information to help with care planning.</p> | <p>Focus groups were appropriately used to gather staff's opinions and perspectives. It is unclear how the 9 homes in the sample were selected and the sample of staff was not described. Thematic analysis was used but there is no further information on analysis. However, a large number of quotes are included and the link to literature shows logical progression from data to findings.</p> |

Appendix E: Ethics Approval



National Research Ethics Service

The National Hospital for Neurology and Neurosurgery
& Institute of Neurology Joint REC

Research & Development

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KT2 7LB
Cur Ref: 09L112
03 April 2009

Dear Ms Wood

Full title of study: How decisions are made by and for older residents with dementia in residential care homes. What is the relationship between these decisions and dignity?
Version 1

REC reference number: 09/H0716/12

The Research Ethics Committee reviewed the above application at the meeting held on 19 March 2009. Thank you for attending to discuss the study

Ethical opinion

Members of the Committee present found the study to be ethical and approved the study with conditions as follows:

- Please justify use of Mini Mental State Examination tests. We feel the test may be intrusive and are unclear how the result links to the study aims and objectives.
- A13 – The committee were unclear if the face to face interview & the audio recording will be done as separate activities or at the same time. Clarification is requested.
- A41 – States data will be stored on the researcher's PC at home. The researcher is advised this is unlikely to meet with Data Protection Act requirements regarding storage of confidential data. Please clarify arrangements

The committee welcomed the opportunity to discuss risk of bias in recruitment.

The researcher will also be given the following general advice for consideration:

Regarding the Patient Information Sheet (PIS)

- Under the heading "Why has the resident been invited?" mentions observation will be done. The PIS should state why and what will be observed.
- Under the heading "What will happen to them if they take part?" Participants

This Research Ethics Committee is an advisory committee to London Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within
the National Patient Safety Agency and Research Ethics Committees in England

- can become distressed and how this would be handled should be mentioned.
- Under the heading "Who has reviewed this study?" – This should be changed to 'This study has been reviewed by the National Hospital for Neurology & Neurosurgery & the Institute of Neurology Joint Research Ethics Committee

Regarding the Consent form

Please note consent for another is not legally recognised in England, some forms will therefore be assent forms rather than consent forms

- The following paragraph should be included where relevant: "I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from [company name] from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records". (or similar).

Mental Capacity Act 2005

I confirm that the committee has approved this research project for the purposes of the Mental Capacity Act 2005. The committee is satisfied that the requirements of section 31 of the Act will be met in relation to research carried out as part of this project or, or in relation to a person who lacks capacity to consent to taking part in the project

Ethical review of research sites

The Committee agreed that all sites in this study should be exempt from site-specific assessment (SSA). There is no need to submit the Site-Specific Information Form to any Research Ethics Committee. The favourable opinion for the study applies to all sites involved in the research.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission at NHS sites ("R&D approval") should be obtained from the relevant care organisation in accordance with NHS research governance arrangements. Guidance on applying for NHS permission is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Approved documents

The documents reviewed and approved at the meeting were:

| Document | Version | Date |
|-----------------------------------------|---------|------------------|
| C.V. - Julia Wood | 1 | 09 February 2009 |
| Letter to care home manager | 1 | 09 February 2009 |
| Interview Schedule - Staff | 1 | 07 January 2009 |
| Interview Schedule - residents | 1 | 07 January 2009 |
| Participant Consent Form: for residents | 1 | 07 January 2009 |

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| Participant Consent Form for staff & relatives | 1 | 07 January 2009 |
| Participant Consent Form for consultants | 1 | 07 January 2009 |
| Participant Information Sheet for residents | 1 | 16 January 2009 |
| Participant Information Sheet for nominated consultants | 1 | 06 January 2009 |
| Participant Information Sheet for staff | 1 | 06 January 2009 |
| Participant Information Sheet for personal consultants | 1 | 06 January 2009 |
| Participant Information Sheet For Relatives | 1 | 06 January 2009 |
| Questionnaire Mini Mental State Examination | 1 | 19 February, 2009 |
| Interview Schedules Topic Guides | 1 | 07 January, 2009 |
| Covering Letter | 1 | 09 February, 2009 |
| Protocol | 1 | 09 February 2009 |
| Investigator CV | 1 | 09 February 2009 |
| Application | 5.6 | 09 February 2009 |

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

| | |
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| 09/H0716/12 | Please quote this number on all correspondence |
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With the Committee's best wishes for the success of this project

Yours sincerely


Ms Katy Judd
Chair

Email: S.Vandeyar@ion-ud.ac.uk

Enclosures: List of names and professions of members who were present at the meeting

Copy to: Professor Paul Wainwright

Appendix F: Interview Topic Guides

Interview Topic Guide. Residents

- What sort of decisions are made by or for you?

Prompts

I am not just asking about major decisions but routine everyday decisions too.

- Which decisions do you consider to be important?
- Who makes those decisions?

Prompts

I would like to ask about each individual decision and who makes them.

Do you get the opportunity to make the decisions you would like to?

- How is it decided who should make the decision?

Prompts

Who is involved?

Have you been asked who should make decisions on your behalf if you are unable to?

Who would you like to be involved in decisions that affect you?

- Have you been involved in the writing of your care plan?
- Have you seen your care plan?
- Would you like to be more involved?
- When a decision needs to be made, what is the process?

Prompts

Please use examples of specific decisions already identified.

Do you know what processes are involved when a decision affecting you is made?

- What values underlie the way decisions are made?

Prompts

Why do you make the decisions the way you do?

- How do you think the decision making process affects you?

Interview Topic Guide friends/relatives

- What sort of decisions are made by or for residents?

Prompts

I am not just asking about major decisions but routine everyday decisions too.

- What decisions does your friend/relative make?
- Is your friend relative able to make decisions for them self?
- Do you think your friend/relative has the opportunity to make the decisions they want to make.
- What decisions do you consider most important
- Who makes those decisions?

Prompts

I would like to ask about each individual decision and who makes them.

Would you like to more involved on the decisions made for your friend/relative?

Who do you think your friend/ relative would like to be involved in the decision making process?

Do you think your friend/relative is involved in decisions whenever it is possible?

- How is it decided who should make the decision?

Prompts

Who is involved?

Have you and/or your friend/relative been asked who should make the decision if your friend/relative cannot make the decision themselves?

- Have you been involved in the writing of the care plan?
- Have you seen the care plan?
- Would you like to be more involved?
- When a decision needs to be made, what is the process?

Prompts

Please use examples of specific decisions already identified.

Do you know much about the decision making process?

- What values underlie the way decisions are made?

Prompts

Why do you make the decisions the way you do?

- How do you think the decision making process affects the residents?

Interview Topic Guide, Staff

- What sort of decisions are made by or for residents?

Prompts

What decisions can residents make for themselves?

I am not just asking about major decisions but routine everyday decisions too.

- What decisions do you consider most important
- Who makes those decisions?

Prompts

I would like to ask about each individual decision and who makes them.

- How is it decided who should make the decision?

Prompts

Who is involved?

- When a decision needs to be made, what is the process?
- Do you involve the resident and their friends and relatives in the writing of care plans?
- Do you show the resident and their friends and relatives their care plan?

Prompts

Please use examples of specific decisions already identified.

- What values underlie the way decisions are made?

Prompts

Why do you make the decisions the way you do?

- How do you think the decision making process affects the residents?

Appendix G: Template for taking information from notes

DOB

Date admitted to Home

Next of Kin/Contact in an emergency

Lasting power of attorney

Diagnoses

Biographical information

Mini Mental State Exam score

Risk assessments

Care plans

Signatures on care plans/evidence of who was involved in planning

Evidence of advanced planning for illness or end of life

Any other documentation about decisions

Appendix H: Peer scrutiny

Conferences and Presentations

Wood J. *Presenting research findings to participants*. Oral presentation 2008 Postgraduate Research Conference. Faculty of Health and Social Care Sciences. Kingston University, St George's University of London, England (Award for best presentation: peer assessed).

Wood J. *How decisions are made by and for older residents with dementia in residential care homes: what is the relationship between these decisions and dignity*. Poster presentation 2009 European Academy of Nursing Sciences, Summer School. Turku, Finland.

Wood J. *Autonomy in the care of people with dementia*. Oral presentation. 2009 International Centre for Nursing Ethics Conference. Nursing Ethics. Looking Back, Moving Forward. University of Surrey, England.

Wood J. *Decisions-making by and for older people in a care home*. Poster presentation. 2010 European Nursing Congress. Older Person: The Future of Care. Rotterdam, Netherlands.

Wood J. *How decisions are made by and for older residents in residential care homes. What is the relationship between these decisions and dignity?* Oral presentation. 2010 Grounded theory and nursing ethics workshop. Theological and Philosophical University of Vallendar, Germany.

Wood J. *Decisions-making by and for older people in a care home* Poster presentation 2011 Research Conference. St George's University of London, England.

Wood J. *The Who, What and How of Decision Making: A Case Study of a London Care Home for Older People* Poster presentation 2011 European Academy of Nursing Sciences, Summer School. Lund, Sweden.

Publications

Wood J (2010) Book Review Edwards SD, Nursing ethics: a principle-based approach. second edition. *Nursing Ethics* 17(4) 532

King L and Wood J (2011) Reflection on a grounded theory and nursing ethics workshop. *Nursing Ethics* 18(2) 272-3

Wood J (2011) Review of Nordenfelt L ed. 2009: Dignity in care for older people. Chichester: Wiley-Blackwell. *Nursing Ethics* 18(3) 459

Peer Groups

Workshops (European Nurses Grounded Theory Group 2011) A grounded theory methodology group of European nurses was established to enable peer scrutiny.

Summer School: European Academy of Nurses (2009, 2010, 2011) where PhD students have shared their work with colleagues from across Europe.

Appendix I: Table E. Description of Participating Residents

| Name | Gender | Age range | First language English? (If no able to understand and speak English) | Mini Mental State Exam | Length of stay in care home (previous home(s)) | Mobility | Biographical details |
|--------------|--------|------------|-------------------------------------------------------------------------|------------------------|---------------------------------------------------|--------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| David *# | Male | 80-89 | Yes | 0 | < 6 months | Immobile, transferred with hoist. | Born and brought up in UK Married One daughter Family visited regularly Part of life spent in institutional settings with group living Skilled manual work, supervisory Had had a hard life Dementia, a number severe physical problems Mostly in his own room Lived with his wife |
| Eleanor *# | Female | 90 or Over | No (No) | 0 | <2 years but >5years | Limited mobility with a stick | Born and brought up outside UK Widow Two children Professional job Dementia, understood and spoke little English because of dementia Lived with her son |
| Geraldine ** | Female | 80-89 | Yes | 29 | <5 years | Fully mobile without a mobility aid. | Born and brought up outside UK Never married No close relatives living near by |

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| | | | | | | | <p>Friends visited irregularly</p> <p>Professional job</p> <p>Part of life spent in institutional settings with group living</p> <p>A number of minor physical problems but cognitively well</p> <p>Mostly in own room</p> <p>Lived in institutional setting with group living</p> |
| Ilene* | Female | 80-89 | Yes | 5 | < 6 months | Fully mobile without a mobility aid. | <p>Born and brought up in UK</p> <p>Never married</p> <p>Two surviving sisters and nephews and nieces</p> <p>Irregular visitors</p> <p>Factory worker</p> <p>Dementia, communication problems</p> <p>Lived alone</p> |
| Iris **## | Female | 70-79 | Yes | 8 | < 6 months | Fully mobile without a mobility aid. | <p>Born and brought up in UK</p> <p>Never married</p> <p>Late brother's wife and nephews and nieces</p> <p>Regular visitors</p> <p>Clerical work</p> <p>Dementia</p> <p>Lived alone</p> |
| Jeanna ** | Female | 80-89 | Yes | 0 | < 6 months | Wheel chair bound. Transferred in a hoist. | <p>Born and brought up in UK</p> <p>Widow</p> <p>Four children</p> <p>Regular visitors</p> <p>Clerical work</p> <p>Dementia</p> <p>Living alone</p> |
| Karen ** | Female | 80-89 | Yes | 17 | <2 years but | Wheel chair bound. Transferred in a | <p>Born and brought up outside UK</p> <p>Never married</p> |

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|--------------|--------|-------|-----|----|----------------------------------------|----------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| | | | | | >5years | hoist. | Nephews and nieces Irregular visitors Part of life spent in institutional settings with group living A number of physical problems and longterm psychiatric condition Lived in institutional setting with group living |
| Katherine ** | Female | 70-79 | Yes | 30 | < 6 months (>2years but <5years) | Fully mobile with a walking frame but became breathless after short distances. | Born and brought up in UK Twice married Three daughters Regular visitors A number of physical problems but cognitively able Lived in another care home |
| Kieran ** | Male | 70-79 | Yes | 24 | >6 months but <2 years | Wheel chair bound. Moved from bed to chair with hoist. | Born and brought up outside UK Never married No family in UK Regular visits from former colleagues Professional job Part of life spent in institutional settings with group living Lived part of his life outside Europe A number of severe physical problems Mostly in own room Lived alone |
| Laura ** | Female | 70-79 | Yes | 28 | <5 years | Fully mobile inside and outside without walking aid. Had a fall during the data collection period. | Born and brought up in UK Never married Two brothers, not living locally Regular visits from friends and former colleagues Worked in social care Part of life spent in institutional settings with group living Physically and cognitively able Lived in institutional setting with group living |

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| Nelly **## | Female | 70-79 | Yes | 29 | < 6 months | Immobile, unable to weight bear. Moved from bed to chair with hoist. | Born and brought up in UK Widow Three children Regular visitors Physical problems and longterm psychiatric condition Lived alone |
| Nora ** | Female | 70-79 | Yes | 29 | >6 months | Wheel chair bound and needs a hoist for transfer. | Born and brought up in UK Widow One son and two grandchildren Irregular visitors Office worker Severe physical problems Lived alone |
| Norman ** | Male | 80-89 | Yes | 30 | < 6 months (<5 years) | Able to mobilise short distances with a walking frame, e.g. to and from the toilet. | Born and brought up in UK Never married Brother and niece Regular visitors Clerical job A number of physical problems but cognitively able Mostly in own room Lived in another care home |
| Pam* | Female | 80-89 | Yes | 3 | < 6 months | Walks with a stick but is unsteady and has had a number of falls. | Born and brought up outside UK Widow Four children Regular visitors Manual job Dementia and a number of physical conditions Lived alone |
| Philippa * | Female | 70-79 | Yes | 27 | >6 months but | Wheel chair bound. | Born and brought up outside UK Never married |

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| | | | | | <2 years | | No relatives in UK Regular visits from former colleagues Part of life spent in institutional settings with group living Severe physical problems Lived in institutional setting with group living |
| Portia * | Female | 90 or over | No (No) | unknown | >6 months but <2 years | Able to mobilise short distances with a walking frame, e.g. to and from the toilet. | Born and brought up outside UK Widow One son Regular visitor A number of physical problems Mostly in own room Lived alone |
| Queenie* *# | Female | 90 or over | Yes | 8 | < 6 months | Unable to walk but could weight bear. | Born and brought up in UK Widow No family Regular visits from friends Clerical job Dementia, a number of physical conditions Lived alone |
| Ruth *# | Female | 80-89 | Yes | 0 | < 6 months | Mobile with the use of a walking stick. | Born and brought up in UK Widow Niece Regular visits from family and friend Office work Dementia Lived alone |
| Vera* | Female | 80-89 | Yes | 30 | >6 months but <2 years | Wheel chair bound. | Born and brought up outside UK Widow No relatives in UK Irregular visits from family and friends |

| | | | | | | | |
|---------------|------|-------|-----|----|----------------------------|---------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| | | | | | | | Office worker A number of physical problems but cognitively able Lived alone |
| Victor **# | Male | 80-89 | Yes | 20 | <2 years but >5years | Wheel chair bound. transferred using hoist. | Born and brought up outside UK Never married Nieces and nephews Regular visitors Had had a hard early life A number of physical problems and longterm psychiatric problems Lived alone |

*Only observed
**Observed and interviewed
Relative interviewed
##Resident and relative interviewed together

Appendix J: Table F. Description of Participating Relatives and Friends

Table F Participating relatives and friends

| Name of relative | Relationship to resident | Age range | Biography |
|------------------|--------------------------|-----------|-----------------------------------------------------------------------------------------------------------------------------|
| Carol | Niece (of Victor) | 50-59 | Close relationship Visited twice a week Nearest relative (along with her siblings) Retired professional Single |
| Christina | Wife (of David) | 80-89 | Married > 50 years 3 adult children Visited daily Office worker prior to marriage |
| Derek | Son (of Eleanor) | 60-69 | Visited daily Retired professional Single |
| Heather | Sister in law (of Iris) | 70-79 | Close relationship. Nearest relative Visited twice a week Retired retail worker Widow |
| Jane | Niece (of Ruth) | 60-69 | Close relationship Nearest relative Visits weekly Retired civil servant Married |
| Molly | Daughter (of Jeanna) | 60-69 | Visited weekly Retired office worker Single |
| Patricia | Friend (of Queenie) | 60-69 | Employed by Queenie as a cleaner for 15 years Queenie had no relatives but many friends Visited fortnightly Single |
| Una | Daughter (of Nelly) | 50-59 | Visited daily Nearest relative along with her siblings Professional working full-time Single |

Appendix K: Open Codes

What constitutes a decision maker

- Resident-I'm not making decisions
- Resident-decisions unimportant
- Resident-deciding everything
- Resident doesn't make decisions
- Resident will speak out
- Resident feels secure
- Resident lets others take on responsibility

When a resident decides

- Resident decides
- Staff assist resident to enact decision
- Resident chooses proxy
- Resident manages own money
- Physical independence increasing choice
- Staff-Resident gives nonverbal signals
- Staff-Resident choice, priority over relative

Facilitators and barriers

- Staff accommodate residents' choice
- Staff facilitate residents to decide
- Risk assessment
- Negotiating with resident
- Catastrophising risk
- Restricting resident with capacity (risk)
- Resisted care, abuse
- Resisted care, try later
- Explain and persuade
- Encourage "wise behaviour" information rationing
- Clean resident for benefit of all
- Staff say staffing levels adequate

Table G. Residents behaviour and characteristics that affect their decision making

| Facilitators to residents deciding | Barriers to residents deciding |
|-------------------------------------|-------------------------------------|
| Resident-insisting | Resident-grateful |
| Resident-organising | Resident-not expecting choice |
| Resident-showing staff not an idiot | Resident-passive |
| Resident-asking for what they want | Resident-lacks faith in own ability |
| Resident-taking control | Resident-low expectations |
| | Physically unable |
| | Resident-cognitive impairment |

Routines, systems and policies

- Limited choice
- Dissatisfied with choice
- Not interested in activities offered
- Inflexible meal times
- Clothes sellers come to home

Relatives impact on decision making

- Residents seek relatives advice
- Resident decides and relatives enact decisions
- Resident passes decisions to relatives
- Resident appreciates relative’s help
- Relative considers resident decision unwise

Table H: Codes: Staff facilitating or acting as barriers to residents deciding

| Staff as facilitators | Staff as barriers |
|------------------------------|---------------------------------------------------------|
| Assisted executing decisions | Staff not asked who’s nominated decision maker |
| Staff listening | Staff English language poor |
| Offering choice | Staff not reacting appropriately to resident’s requests |
| Staff facilitating choice | Has to wait too long |
| | Not enough staff |
| | Staff don’t talk to me |
| | Staff don’t listen |

Nominating a proxy decision maker

- Sense/intelligence
- Feeling of safety with family
- Family know me
- Family love me
- Staff not asked about proxy decision maker
- Does not want to burden family
- Staff to decide- no alternative
- Power of attorney

Advance planning decisions

- Has considered advance decisions
- Staff don't have time
- Talking about end of life
- Advance decision made
- Resident deciding
- Hospital admission default position
- No discussion of advance decisions
- Doesn't think that advance decisions are worth the bother
- Doesn't think that staff would bother with advance decisions

Relatives perspective on advance planning decisions

- Has considered advance decisions
- Staff don't have time
- Talking about end of life
- Advance decision made
- Resident deciding
- Hospital admission default position
- No discussion of advance decisions
- Doesn't think that advance decisions are worth the bother
- Doesn't think that staff would bother with advance decisions

Table I: Staff decides

| <i>Staff factors</i> | <i>Relative involvement</i> | <i>Resident characteristic</i> |
|---------------------------------------------------|--------------------------------------------------------|--------------------------------|
| Staff decide | Staff learn what involvement relative wants | Resident too easy going |
| Decisions not part of care workers role | Staff contact relative in emergencies | Resident cannot decide |
| care workers decide | Hospital admission without consultation with relatives | Resident compliant |
| Staff persuade | Relatives unrealistic expectations | Resident resists care |
| Staff not recognising non-verbal signals | Resident hospitalised at relative`s insistence | Resident has little choice |
| Staff override resident to deliver necessary care | Relative involved to persuade resident | |
| Cannot neglect | Relative cannot decide alone | |
| Keep returning to resident reluctant to have care | Relative`s best interest not resident`s | |
| 24 hour care | | |
| Fear of blame | | |
| Collaborative decision making | | |
| Capacity test to avoid blame | | |
| Monitoring resident with capacity | | |
| Fear of risk | | |

Advanced planning, staff`s perspective

- Planning when death is expected
- Do not plan when resident is well
- Permission from relative not to hospitalise
- Exoneration from blame
- Resident decides on “clinically inappropriate” treatment

Authority for and underpinning values in staff decisions

- Resident compliant
- Medical best interests
- Keeping resident safe
- Decision in a crisis
- Necessity to deliver minimum care

Relative decision making

- Relative needs more information from staff
- Relative's concern about everyday issues
- Relative satisfied with staff deciding
- Lack of activities
- Relative cannot provide suggestions
- Involve family when resident lacks capacity
- Relative involvement in care planning

Facilitators and barriers to relative involvement

- Hasn't had opportunity to tell staff about resident
- Doesn't know which staff member to talk to
- Relative insists
- Gets it done
- Relatives' responsibility
- Won't insist (personality)
- Low expectations
- Not private patient
- Relative perceives low staffing levels
- Unpleasant job, (so staff not always providing good care)
- Finances a burden
- No system for formal communication
- Staff not volunteering information

Relative reluctant to be involved

- Relative does not feel better placed than staff to make decisions

Relatives rational for involvement in decision making

- Duty
- Affection
- Family reciprocity
- Family ties
- Other family members won't help
- Relative involved because no choice

- Guilt (putting relative in a care home)
- Resident wanted to be cared for by relative
- Limit to duty
- Friendship

Authority and underpinning values for relatives' decision making

- Resident wants relative involved
- All the family involved
- Best interests
- Well-being
- Relative ensures resident is well looked after
- Family values
- Delivering necessary care (persuasion)
- Best medical interests
- Quality of life
- Substituted judgement
- Decide on what the relative would want for themselves

Decision made by doctor

- Doctor knows best
- Doctor not making the right decision
- Doctor holds power
- Doctor not always trusted
- Resident not informed
- Doctor decides
- Doctor not making the right decision
- Doctor needing to earn trust
- Takes doctor's advice
- Get information from doctor (before making a decision)
- Relative takes doctor's advice
- Relative gets information from doctor (before making a decision)