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Understanding the communication of older people with dementia living in residential care

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Abstract

This thesis explores the communication of a group of older people with dementia living in a residential care home and specifically, seeks to understand how living with dementia in a care home influences communication. The study draws broadly on a symbolic interactionist perspective and uses an ethnographic, inclusive, video methodology. In so doing, the study grounds the research in the experiences of the older residents with dementia and explores communication as it is interwoven with social life.

The empricial data, on which this thesis is based, were gathered over the course of six months in one residential care home in Central Scotland. Analysis of these data, in conjunction with the theoretical literature informing the study, led to the development of a framework and a set of concepts to understand the communication of the older people with dementia living in residential care. This framework was used to examine the ways in which the older residents' experiences of institutionalisation, ageing, and dementia, generally, and of life in the care setting, specifically, influenced their communication. The findings revealed that the older residents made diverse meanings of their experiences in the home, and that many of the meanings that they made were threatening to their self-identity, self-determinacy and social relationships. The residents engaged in a range of strategies to respond to the impact of these meanings and to negotiate their life in the care home.

The research presented in this thesis has many implications for understanding the experiences of older people with dementia in residential care. In particular, the research highlights the need for a new social understanding of dementia, that examines the experience of dementia in relation to broad structural and cultural processes and that seeks to promote the social inclusion and citizenship of older people with dementia.

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Contents

Chapter 1

Introduction

1.0 Overview

This thesis is an exploration of the communication of older people with dementia living in residential care. The study adopts an ethnographic, inclusive, video methodology to examine the communication of a group of older residents with dementia in relation to the meanings they make through their interactions in the world and the ways in which they respond to those meanings. Central to the study is recognition of the pivotal place of communication in social life. Drawing broadly on a symbolic interactionist perspective, in particular as elucidated by Blumer (1969), this study is grounded in a conceptualisation of communication as the means by which people come to know themselves and the world around. Thus, this is not just a study of how people with dementia communicate, but of how they negotiate life with dementia in a residential care setting.

The thesis both draws on, and feeds into, the developing social model of dementia. By examining the communication of older people with dementia themselves, this study challenges the dominance of biomedical perspectives on dementia and contributes to the growing body of research seeking to understand the lived experience of dementia. Furthermore, the study builds on moves in the field of dementia to develop innovative methods to both elicit the

perspectives of people with dementia directly and to facilitate their inclusion in the research process. The key new contribution of the thesis is the development of a theoretical framework through which to understand the communication of older people with dementia in relation to the broader social context in which they live.

Communication is an important issue in the field of dementia. The cognitive impairments associated with dementia may lead to memory loss, disorientation and a global slowing of cognitive functioning, resulting in problems communicating (see Bourgeois, 1991 for a review). However, research has shown that people with dementia in many situations are able communicators and active agents in the world, continuing to make meaning of both themselves and the world around, despite the cognitive impairments they experience (e.g. Crisp, 1995; Gubrium, 1975; Hubbard et al, 2002; McColgan, 2001). This disparity in findings has led many to conclude that the communication problems of older people with dementia are a function of both their experiences of dementia and of the interpersonal and institutional contexts in which they find themselves (e.g. Kitwood, 1997; Sabat, 2001). To date, understanding of the communication of people with dementia has been limited to examining their communication in relation to the attitudes and abilities of their carers. There has been little consideration of how the broader social context influences communication, or indeed how older people with dementia themselves manage these influences.

The framework developed over the course of this thesis provides an understanding of the ways in which having dementia, being old and living in a residential care home influence the communication of the residents. Specifically, the thesis examines the ways in which the communication of the older residents is influenced by the meanings they make of the stimuli they encounter in the world and explores how the residents respond to these meanings in relation to the extent to which they threaten or support their self-identity, self-determinacy and social relationships. In so doing, the thesis examines the influence of processes of marginalisation and social exclusion on the communication and experiences of older people with dementia living in residential care. Thus the study has implications for policy that seeks to support the communication of older people with dementia living in residential care both in relation to their institutional context and in their interactions with society more generally.

1.1 Policy context

Dementia is a common condition amongst older people affecting 5% of people over 65, and 30% of those aged 80 and above (Ritchie and Lovestone, 2003: 1759). Furthermore, recent research suggests that due to population ageing, the prevalence of dementia is increasing, and between the years 1998 and 2031 the number of people with the condition in England is expected to rise by 66% (Comas-Herrera et al, 2003:2). The high levels of care needed amongst this population make a significant issue for policy makers. Not only does dementia affect the ability of people who have the condition to complete tasks

of daily living, but physical disability and mental health problems are common amongst older people with dementia (MRC CFAS and RIS MRC CFAS, 1999: 1109; Ritchie and Lovestone, 2003:1759). A recent survey found that 49% of people with only a cognitive impairment required help on a daily basis with personal care, with this figure rising to 80% of those with a combined cognitive and physical disability (MRC CFAS and RIS MRC CFAS, 1999).

The care needs of most people with dementia are met in their own homes, mainly by informal carers (Innes, 2002: 487), though approximately 23% of people with dementia and a physical disability rely solely on formal home care (MRC CFAS and RIS MRC CFAS, 1999: 1109). A significant minority of people with dementia live in institutional care settings. Estimates of the numbers vary depending on the study and range from 20% to 45% (Innes, 2002:487). People with dementia account for a high proportion of those in institutional care settings. Again figures vary, the recent MRC CFAS survey found 46% of those living in institutions had diagnostic levels of cognitive impairments (MRC CFAS and RIS MRC CFAS, 1999:1110), whilst research in Scotland found the figure to vary between 30% and 70% depending on the setting (Gordon and Spicker, 1997). Thus, institutional care plays a major role in the response by society to meeting the needs of people with dementia and constitutes an important context for understanding the experience of dementia. The majority of this care was traditionally provided in two distinct kinds of settings, nursing homes and residential care homes. Residential care homes, such as the one in this study, only provide support with personal care as opposed to nursing homes which are

also registered to provide nursing care. Recent legislation in Scotland has blurred this distinction and legally all residential facilities for older people, now termed 'care homes', may provide whatever personal and nursing care is needed by the resident. This legislation seeks to prevent the need for residents to move institutions as their care needs increase (Scottish Executive, 2001).

The majority of the literature on residential care homes has been critical of the care provided in such settings (Bland, 1999:539). In 1947, the Rowntree Inquiry found the quality of care of older people in institutions to be very poor, with few amenities and little space for private belongings or activity (Bernard and Phillips, 1998). This finding was echoed in research by Townsend which elucidated the many ways in which care home routines forced residents into a position of dependence (Townsend, 1962; 1981). This, he argued, was because they grew from the workhouse model of provision for older people and able-bodied poor, which was designed to be so unpleasant that no one would enter voluntarily (Townsend, 1981:6). Research carried out in the late 1970s and early 1980s revealed that little had changed since Townsend's 1962 study and in particular highlighted the low levels of interaction in which older people in institutional care settings engaged (Godlove et al, 1982; MacDonald et al, 1985).

In response to these and other such findings, a number of best practice guides have been published making recommendations regarding the provision of residential care. Three particularly influential guidelines were: Home life: a code

of practice for residential care (Centre for Policy on Ageing, 1984); the sequel A Better Home Life (CPA, 1996) and Homes are for Living In (Department of Health, 1989). These guidelines have proven influential in shaping both the provision of residential care across the UK and recent care standards. Building on Home Life, A Better Home Life outlined several key principals that should underlie care. These were: respect for privacy and dignity; maintenance of self-esteem; fostering independence; choice and control; recognition of diversity and individuality; expression of beliefs; safety; responsible risk taking; citizen's rights; sustaining relationships with relatives and friends; opportunities for leisure.

These guidelines proved very influential in shaping the public response to improving care in institutional care settings. They both prompted the initial development of a system of inspection and regulation of care homes and informed the content of the Care Standards against which homes are inspected. The most recent standards in Scotland, the National Care Standards: Care Homes for Older People (Scottish Executive, 2002) resulting from the Regulation of Care (Scotland) Act 2001, are based on the values of dignity, privacy, choice, safety, realising potential and equality and diversity. These standards cement the role of the older person in determining their care themselves, reflecting moves more generally to frame users of health and social care services as consumers, as opposed to patients (Peace et al, 1997; Walker and Warren, 1996). In addition, the Standards highlight the need to ensure older residents continue to engage in normal activities of daily life and be

supported to maintain links with family, friends and their community. Similarly the Department of Health Care Homes for Older People: National Minimum Standards (D of H, 2001) highlight the importance of privacy, dignity and respect in care. These Department of Health Standards acknowledge that 'the test of whether these principals are put into practice or not will be a matter for the individual resident's own judgement' (2001: 7). Furthermore they highlight the need for the staff, and by implication the care regime, to regard the resident as a 'real person with desires, hopes and expectations.' (2001:8).

The introduction of care standards and inspection and regulation has been found to have improved the quality of care provided in residential care settings (Peace et al, 1997). However, as Bartlett and Boldy (2001:11) argue, standards themselves do not necessarily lead to improvements in quality of care. Despite the improvements noted by Peace et al over the course of the late 1980s and early 1990s, research in the field of dementia during that time found the quality of care provided for people with dementia in many institutional care settings to be inadequate (e.g. Kitwood and Bredin, 1992). These findings prompted an increased interest in the situation of people with dementia and the particular issues involved in providing good care to this population (e.g. Kitwood, 1993; Marshall, 1997). In the UK these insights were encapsulated by Person Centred Care, an approach to understanding people with dementia and their care that highlighted the negative influence of poor caring environments and interactions on the personhood and quality of life of the person with dementia (Kitwood, 1997). Research has shown that adopting a person centred approach to care

has many positive outcomes for the person with dementia (Bredin et al, 1995), but also that it is a challenging enterprise, demanding significant skill and motivation on the part of the carer (Gibson, 1999).

Despite the now widespread recognition of the particular needs of people with dementia in care, the National Care Standards: Care Homes for Older People (Scottish Executive, 2002) makes no mention of the possible barriers to implementing the standards with older people with dementia, or how they might be overcome. For example, the Scottish Standards assure older people that their need to keep in contact with family and friends, and that their right to comment on the services they receive will be supported. Furthermore, they highlight the responsibility of care homes to put mechanisms in place for supporting the communication of residents for whom English is not their first language or who rely on communication aids. No suggestion is made as to how care homes should support people with dementia in these tasks. Recent research found that people with dementia could be supported to give their perspectives on care in the context of a one to one relationship. However, this demanded a considerable input of time and commitment as well as imagination on the part of the carer (Allan, 2001).

The issue of meeting the needs of older people with dementia in care homes is one that is only going to increase. Comas-Herrera et al (2003:3) estimate that as the number of people with dementia increases by 66% over the next 30 years, so the number of people with dementia in institutional care settings will

increase by 63%. This is proportionately greater than the increase in numbers of older people in institutions, which is expected to increase by 52%. Therefore the care homes of the future will need to find new and innovative ways to ensure that an increasing proportion of residents with dementia are able to enjoy the quality of care promised by both sets of Care Standards. Improving understanding of the ways in which living with dementia in a residential care home influences the communication of older people and finding ways to support their communication must be central to any moves towards improving quality of care.

1.2 Aim and Research Questions

The overall aim of the thesis is to explore the influence of living with dementia in a residential care home on the communication of the older residents. This aim is met by addressing the following research questions.

1. What meanings do the older residents make of their life with dementia in the care home?

2. How do these meanings impact on the self-identity, self-determinacy and social relationships of the older residents with dementia?

3. How do the older residents with dementia respond to these meanings through their communication?

4. What are the implications of the findings for understanding the communication of older people with dementia living in residential care?

Over the course of this thesis, the study is described and justified, and the research questions answered. The background to the study is presented in chapter two. Theoretical and empirical research on the experiences of dementia, ageing, disability and institutionalisation is reviewed, and the importance of understanding the experience of older people with dementia living in care in relation to their experiences of marginalisation and exclusion, highlighted. Furthermore, the need for examination of the communication of older people with dementia to be informed by a theoretical framework is stressed.

Chapter three presents the theoretical and methodological approaches used in this study to understand how living with dementia in a care home influences the communication of older people. The symbolic interactionist perspective is described and the way in which it is used in this study outlined. The methodological implications of this approach are examined and the use of ethnography, inclusive methodologies and video reviewed. In chapter four, the ways in which the methodological approach was put into practice to collect and analyse the data is outlined. This chapter also reflects on the suitability of the methods for researching the experiences of older people with dementia and including them in the research.

In chapters five, six and seven the findings are analysed and discussed in relation to the literature presented in chapter two. Chapter five introduces the analysis, presenting a framework and set of concepts used to understand the

findings. Furthermore the residents whose experiences formed the basis of the study are introduced. In chapter six the influence of being old, having dementia and living in a residential care setting on the communication of the older residents is explored. Specifically, the meanings the residents made of being old, having dementia and living in a care home are examined. The impact of these meanings on the self-identity, self-determinacy and social relationships of the residents, and the ways in which they responded to these threats through their communication are described. Chapter seven examines the communication of the older residents in relation to the specific institutional context in which they were living. The meanings the residents made of the space and care regime in the home are described and the ways in which these aspects of the institutional context influenced their communication considered. In chapter eight these insights are brought together and the implications of the findings for supporting the communication of people with dementia, as well as for understanding subjective experiences of marginalisation and exclusion generally and dementia specifically are then examined.

Chapter 2

The communication of older people living with dementia in care: theoretical and empirical perspectives

2.0 Overview

This thesis is an exploration of the ways in which living with dementia in a residential care home influences the communication of older people. As such it is not just a study of how people communicate, or how others can help to this end, but is a study of the everyday lives of older people with dementia in residential care, the meanings they make of the world and themselves and how they respond to these meanings through their interactions with others and the spaces and regimes within which they reside. Thus, rather than building directly on existing practice orientated and psychological research on communication and dementia this study represents a shift in perspective, examining the communication of older people with dementia in relation to their wider social context from a more sociological perspective. A large body of theoretical and empirical literature informs the exploration of the communication of older residents with dementia in this study. This chapter sets the scene for the thesis by presenting this literature in three main sections.

The first section considers different ways in which dementia has been theorised. Four perspectives, or lenses, used to study dementia are examined and the implications for the use of these perspectives, both for understanding dementia and the ways in which dementia is experienced, are discussed. The second section reviews empirical research looking at what we know of the experience of dementia, in particular in relation to communication, self and living in an institutional care setting. The importance of all these aspects of experience to understanding communication is highlighted. The third section considers the wider socio-cultural context for the communication of older people with dementia living in residential care. Research from the fields of ageing, disability, dementia and institutionalisation is reviewed to highlight the ways in which people with dementia are marginalised and excluded at societal and institutional levels. The impact of these processes on the experience and in particular self-identity of the individuals concerned is then considered. First, however, the chapter reviews the literature on the experience of dementia.

2.1 Theoretical perspectives on the experience of dementia

Dementia is the term used to describe a range of disorders that result in progressive cognitive impairment, eventually leading to death (Jacques and Jackson, 2001). To date dementia has been understood primarily as a disease. There is, however, a growing move to understand dementia as an illness, which is to understand it in relation to the way it is experienced by people who have the disease (Lyman, 1998: 50). Understanding of the experience of dementia stems from two broad perspectives, biomedical and social. The biomedical

perspective focuses on the neuropathological causes of dementia and researchers examining the experiences of people with dementia from this perspective do so looking for markers of location and nature of neuronal damage and response to treatment. The social perspective on dementia focuses on the relationship between the experience of dementia and the person's psycho-social and socio-cultural context. These perspectives have greatly influenced the way dementia has come to be understood by researchers working in the field, the general population and people with dementia themselves. This section reviews first, the biomedical perspective, and then, following a discussion of the 'social model of dementia', three social perspectives on dementia: dementia care, critical gerontology and dementia as a disability.

2.1.1 Biomedical perspectives on the experience of dementia

Biomedical perspectives posit that dementia is caused by neurochemical changes in the brain. These affect the transmission of blood, oxygen or nerve impulses around the brain affecting functioning and ultimately leading to death (e.g. Ritchie and Lovestone, 2003). This model identifies several different types of dementia, the most common ones being Alzheimer's disease, vascular dementia, and a mixture of the two (Jacques and Jackson, 2001).

To date, biomedical approaches to dementia have dominated the field, focussing on establishing diagnostic tools (see Wilcock et al, 1999 for a collection of papers): understanding the genetic, neurological and biochemical

processes underpinning the condition (Portera-Sanchez et al, 1994); identifying risk factors (Ritchie and Lovestone, 2003) and searching for a cure to the condition (Melzer, 1998). This work has led to many advances in our understanding of dementia. Research has led to the identification of a gene implicated in dementia; the development of a range of clinical and neuropsychological tools to diagnose dementia; the identification of risk (e.g. smoking, low social class and age) and protective factors (e.g. antioxidants and oestrogen) (Ritchie and Lovestone, 2003). There are, however, still many questions to be answered. Several drugs to slow the progression of Alzheimer's type dementia are on the market (Melzer, 1998), although it is still impossible to make a differential diagnosis of Alzheimer's type dementia with certainty (Wilcock et al, 1999). Furthermore the mechanisms of Alzheimer type dementia are poorly understood (Ritchie and Lovestone, 2003).

The biomedical approach to dementia has dominated the field including psychological, nursing and social gerontological research in the area (Lyman, 1989). During the 1980s and 90s, in particular, many researchers working in these areas embraced the view of dementia as a problem of the individual and sought to understand the many psycho-social manifestations of the disease. This research tended to focus on the development of tools with which to document the behavioural, emotional and cognitive deficits associated with dementia and evaluate the success of the 'interventions' put in place to overcome them. Thus agitation, aggression (Allen-Burge et al, 1999) and positive affective response (Smith, 1995) were all identified as psycho-social

problems of dementia. Research examining the care of people with dementia revealed the burden experienced by family carers (e.g. Zarit, 1999) and the difficulties experienced by services working to meet the needs of this population (e.g. Beck, 1999).

The consequence of this research was that people with dementia came to be seen entirely in terms of problems and deficits. This focus on the communication deficits in dementia challenged the extent to which people with dementia had a self and identity. The therapeutic nihilism surrounding the condition was such that caring for people with dementia was seen as an impossible task and service providers and policy makers resigned themselves to abandoning people with dementia to the back wards (Clark, 1999), leaving it to medicine to find a cure.

By the mid 1990s, this nihilism, and the biomedical model it stemmed from, was widely challenged by both people working in the field of dementia care, and critical social gerontologists. Researchers and practitioners working to develop good models of care highlighted the influence of psychosocial and environmental factors on the experience of dementia (Bredin et al, 1995; Kitwood, 1987; Norberg et al, 1986). Critical gerontologists questioned the validity of the biomedical account of dementia and emphasised the socially constructed nature of the experience of dementia (Bond, 1992; Gubrium, 1978; Lyman, 1989). These insights came together into what has been termed the

'social model of dementia', encompassing a number of different understandings of and approaches to the experience of dementia.

2.1.2 Social perspectives on the experience of dementia: the 'social model of dementia'.

The term 'social model of dementia' is somewhat of a misnomer, referring as it does to a range of approaches to and understandings of dementia that focus on the person with dementia themselves as opposed to the pathology underlying the condition. These different approaches are united in their rejection of a purely biomedical understanding of dementia and their focus on the influence of wider social, cultural, institutional or interpersonal factors on the experience of dementia. The perspectives differ in their emphasis on the importance of neuropathy to the experience of dementia, and in the location of their analysis of the person with dementia's experience. For example, dementia care perspectives focus on psychosocial aspects of the experience of dementia in relation to the immediate care environment, whilst critical gerontological perspectives consider the experience of dementia in relation to wider structural and cultural processes. Thus the different social perspectives have very different implications for policy, practice and research. Three distinct social perspectives on the experience of dementia can be identified, stemming from the fields of dementia care; critical gerontology and disability, and are described in more detail below.

2.1.3 Dementia care perspectives

Evaluation of care environments for people with dementia in the early 1980s highlighted the low levels of interaction experienced by people living in them (e.g. Godlove et al, 1982; MacDonald et al, 1985; McCormack and Whitehead, 1981). Previously these low levels of interaction had been attributed to the communicative impairments experienced by people with dementia, however, a few dissenting voices from the field of dementia care challenged these preconceptions. In particular Tom Kitwood (1987; 1988; 1993; 1997) highlighted the low social status of older people with dementia and the poor quality of the caring environments in which many people with dementia lived. He argued that these poor care environments and the resulting malignant social psychology exacerbated the experiences of confusion and impairment amongst people with dementia (Kitwood, 1997:45). Thus he argued that the experience of dementia was not solely the result of neuropathology, but was also influenced by psychosocial and environmental factors (Kitwood, 1987; 1997).

These insights led him to develop the person centred approach to dementia care, which highlighted the need to look beyond dementia and treat every person in care as an individual, responding to their individual needs (Kitwood, 1997). Through this individualised care, he argued, caring environments might support the personhood of people with dementia, the key goal of person centred care. Kitwood (1997) claimed the term personhood to refer to the feeling of still being a person as evidenced by engagement in shared experiences with others, and emphasised the didactic nature of personhood,

which he argued was constructed in interaction with others. Communication was highlighted as being central to the maintenance of people with dementia's personhood and quality of life, with good communication vital to maintaining personhood, whilst poor communication responsible for threatening the personhood of a person with dementia. Kitwood (1997) argued that through the application of person centred care the malignant social psychology, present in so many care environments for people with dementia, could be reduced leading to an improvement in functioning, what he termed rementia. With colleagues in Bradford he devised a tool to measure the extent to which a person with dementia's personhood was supported by any particular care environment, Dementia Care Mapping (DCM) (Bredin et al, 1995).

Those working within person centred care called for the perspectives of the person with dementia to be actively sought, and to 'hear their voice' so that care might be provided to best suit the individual (e.g. Allan, 2001; Barnett, 2000; Dabbs, 1999). Carers were urged to look beyond the so-called 'challenging behaviours' of people with dementia and identify the unmet needs and frustrations expressed through them (Kitwood, 1997). In these ways, caring environments might support the personhood and quality of life of the person with dementia for as long as possible through the progression of the dementia (Kitwood, 1997). This approach has proven highly popular, and in the UK, person centred care has been adopted by policy makers and service providers as the gold standard in dementia care (Adams, 1998).

Kitwood's approach of person centred care has made a significant contribution to advancing understanding of dementia, to changing care practices and improving the quality of life for people with dementia receiving care (Woods, 2002). Furthermore his basic tenet, that social context influences the communication of older people with dementia, is central to this study. There are, however, three key limitations of the perspective as articulated and implemented so far for understanding how living with dementia in a residential care home influences older people's communication. The perspective, although ostensibly giving primacy to the person being cared for, actually masks the agency of the people with dementia themselves by emphasising the role of carers in the maintenance of people with dementia's personhood. For example, in the area of communication, although extensive research has examined how others facilitate the communication of people with dementia (e.g. Berg 1998; Killick and Allan, 2001; Perrin, 1998), there has been less emphasis on the ways in which people with dementia manage their communication themselves (Cook, 2002, appendix A). Secondly, although person centred care stresses the importance of eliciting the perspectives of people with dementia, the emphasis has been very much on eliciting perspectives as they relate to care and in the context of caring relationships. This perspective has shed little light on the experiences of people with dementia not in care settings, and in care settings, relationships between residents have largely been ignored.

The final limitation of the usefulness of the perspective to this study is its conservatism. Whilst in an early paper Kitwood (1987:118) drew on the work of

Foucault to highlight the need to look behind the 'terminal truths' in dementia to see what they 'render invisible', and critiqued much of the medical evidence for dementia, he limited his conclusions to calling for the inclusion of a psychological perspective in understanding the causes of dementia. Furthermore, whilst he commented on the low status of people with dementia in contemporary society, his analyses of their situation has been confined to the culture of care settings. Therefore I would argue that although person centred care might help improve the care of people with dementia in formal care settings, it is not a useful perspective for those looking to understand the experiences of older people with dementia, in particular as they relate to their wider social context. Critical gerontology provides a more useful framework to this end.

2.1.4 Perspectives from critical gerontology

Critical gerontology is a perspective that has dealt more explicitly with the experiences of older people with dementia themselves as opposed to those of their carers. Over the past 30 years there has been a growing body of critical gerontological thought which re-examined the situation of older people in relation to the wider socio-cultural, economic and political processes (e.g. Estes, 1979; 2001; Lynott and Lynott, 1996; Phillipson, 1998; Quando and Reid, 1999; Townsend, 1981; Walker, 1981). This body of literature has highlighted the socially constructed nature of ageing and the ways in which this construction has been used to justify the inequitable distribution of resources to older people and their resulting marginalisation and disadvantage (o.g. Estes,

1979; Phillipson, 1998; Townsend, 1981; Walker, 1999). Despite the applicability of these analyses to the particular situation of people with dementia, many of whom are old, very few gerontologists have considered dementia, and people working in the field of dementia have been slow to pick up on these analyses. The small body of critical gerontological thought in the field has however had a significant impact on the conceptualisation of dementia.

As with the experience of ageing more generally, a number of critical gerontologists have highlighted the extent to which the experience of dementia has been medicalised (Bond, 1992; Gubrium, 1986; Lyman, 1989). Researchers working from this perspective have highlighted how the dominance of biomedicine has resulted in an unnecessary focus on the deficits and impairments of dementia. This focus on biomedicine has been critiqued for sidelining the lived experience of dementia and the influence of socio-cultural factors (Lyman, 1989). Furthermore, by placing responsibility for dementia firmly with clinicians and scientists the medicalisation of dementia has excluded and disavowed the agency of people with dementia themselves (Lyman, 1989).

A number of researchers working in this area have questioned the validity of a biomedical explanation for dementia (Bond, 1992; Gubrium, 1986; Kitwood, 1987, 1988; Lyman, 1989). Gubrium (1986), following examination of transcripts of carers conversations in Alzheimer Society carer support groups in the USA, illustrated the ways in which carers socially constructed the dementia of their relatives by labelling common behaviours in old age as symptoms of dementia.

This, he argued, served to legitimise the concerns of both the carers and the carer organisations. Robertson (1990) extended these arguments to highlight the benefits of the construction of the burden of dementia to both society and the growing army of service providers. Drawing on the work of Goffman (1963), Bond and Corner (2001) highlighted the stigmatised nature of dementia and the way in which this stigma influenced the experiences of people with dementia themselves and the experiences of their relatives, who suffered what Goffman (1963) has termed courtesy stigma as a result of their association with a stigmatised person.

The critical gerontological perspective has been vital in bringing much needed critical analysis to the situation of people with dementia and the beginnings of a theoretical understanding of dementia in relation to wider society. This work, however, is very underdeveloped. Although the arguments notably of Gubrium (1986), Lyman (1989) and Bond (1992) are widely cited, researchers working in the field of dementia have been slow to develop the insights and gerontologists continue to ignore the specific situation of people with dementia. In particular, researchers have been slow to examine the situation of people with dementia in relation to wider social structures and cultural processes (Downs, 2000), with Hulko's (2002) current work being a notable exception. One area where these critiques have been progressed, however, is that of researching the experiences of people with dementia. Lyman (1998) called for more phenomenological inquiry in dementia, highlighting the need for future understandings of dementia to be grounded in the lived experience of people

with dementia themselves. This call, resonating as it does with both the moves in dementia care to 'hear the voice' of people with dementia and the adoption of disability perspectives in dementia (which are discussed in the next section), has been responded to enthusiastically by many researchers. This study seeks to build directly on this body of work both by focusing on the experience of older people with dementia themselves and in relation to the wider social context in which they live.

2.1.5 Dementia as a disability

Over recent years, researchers building on insights from both person centred care and critical gerontology have highlighted the relevance of the social model of disability to dementia, calling for dementia to be seen as 'just another disability' (Gwilliam and Gilliard, 1996; Kitwood, 1997; Marshall, 1998).

The key tenet of the social model of disability is that people with impairments are disabled by a society that is organised in ways that do not accommodate their needs (Oliver, 1990). Central to this model is the distinction between impairment and disability:

> Impairment is the functional limitation within the individual caused by physical, mental or sensory impairment.
> Disability is the loss or limitation of opportunities to take part in normal life of the community on an equal level with others due to physical and social barriers. (Barnes ,1991: 2)

Through such a distinction, proponents of the social model of disability challenged the conceptualisation of disability as a 'personal tragedy' requiring sympathy and compensation from society (Reeve, 2002). Instead they called for disability to be defined as social oppression and disabled people to be seen as 'the collective victims of an uncaring or unknowing society, rather than individual victims of circumstance' (Oliver, 1990: 2). These analyses brought people with different disabilities together under a common banner, and through an accompanying model of emancipatory action, provided means for disabled people to fight their oppression and change society (Barnes et al, 1999). With respect to research, the model of emancipatory action called for a shift in the balance of power in research relations, so that people with disabilities themselves set research agendas, carry out and disseminate research (Barnes, 2003). Through these methods the voices and experiences of disabled people themselves are mainstreamed, reducing their 'othering' by society. 'Othering' refers to the process of establishing certain people (e.g. disabled people, people from minority ethnic groups) as outsiders and not part of 'normal' society, thereby justifying their exclusion at economic, cultural, political and interpersonal levels (e.g. Fine, 1994).

Several of the ideas from the social model of disability as first laid out in the late 1980's and early 1990s have been translated across to dementia. Writers from the field of dementia highlighted the benefits of viewing dementia as a disability first and a disease second in detracting attention from the inevitability of the condition and providing positive solutions to the particular impairments

experienced by people with dementia (Kitwood, 1997; Marshall, 1998). In particular there has been a focus on the ways in which the physical environment might be altered to help people with dementia function despite their impairments. Marshall highlighted many simple ways in which the living environments of people with dementia can be adapted to make them less disorientating and therefore disabling (Marshall, 1997). For example, having glass doors on kitchen cupboards and placing curtains over doors to discourage people from wandering. In addition, technology has been developed to help people with dementia overcome difficulties they experience negotiating their physical surroundings, the most notable example of this being the development of 'Smart Houses' which monitor the actions of the residents through pressure, heat and light sensors relayed to a central control station (Gilliard, 2001).

Viewing dementia as a disability has also encouraged the adoption of emancipatory approaches to research to change the situation of people with dementia. Thus many researchers now actively seek to include their participants with dementia in the research and are seeking innovative methods through which to achieve this is in a meaningful way (Cook, 2003; Mills, 2003; Sabat, 2003; Wilkinson and Hubbard, 2003 and Wilkinson, 2002). However, this work is still in it infancy, and although researchers and service providers in the field are better at involving their participants and service users in decisions affecting them, very few researchers, practitioners or people with dementia themselves are supporting others to drive forward a truly emancipatory agenda for dementia. This research is reviewed in detail in chapter three.

The potential usefulness of the social model of disability for understanding dementia has not as yet been realised or properly assessed. More conceptual clarity and critical analysis of the model is required. To date the social disability model has not, as Oliver (1990) advocates for people with physical disabilities, been adopted seriously as a causal model of dementia, but is instead used as a model for supporting people with dementia (Hulko, 2002). This, I would argue, reflects the dominance of professional and carer perspectives in the field of dementia who have imposed this model on the experiences of people with dementia, and goes against the very spirit of the social model of disability with its focus on activism and working towards the normal participation of people with disabilities in their communities (Oliver, 1990).

The usefulness of this model in taking understanding forward in dementia to date, is further limited by the adoption of a very simplified version of the social model of disability, as first proposed by disability researchers such as Oliver (1990) and Finkelstein (1980). This model has been widely critiqued from within the field of disability for being dominated by the concerns of physically disabled, educated, white, young men and ignoring people with disabilities from marginalised groups in society (e.g. Thomas, 1999). Furthermore, the model has been critiqued for being too simplistic and not accounting for the diversity of the impairments of disabled people. Sally French gives the example of computer aids for visually impaired people not suiting everyone with a visual impairment and makes the point that 'people's problems, even within the same

disability pigeon-hole, differ so much' (French, 1993:45). These critiques are particularly salient to the field of dementia, which is largely experienced by older people already marginalised by their age and which as a condition is manifested in many diverse ways. Finally the social model of disability has been critiqued for focussing on the stigma associated with impairment and ignoring the pain, tiredness and frustration people with many impairments experience (Mulvany, 2000).

The introduction of the concept of disability to understanding dementia has been important in taking the field forward. Just as the social model of disability has been applied usefully within the fields of ageing and mental illness to provide both a model for emancipatory action, and a framework for considering these experiences in relation to wider structural and cultural processes (Mulvany, 2000; Oldman, 2002), so the beginnings of these processes are occurring in dementia. There is an urgent need however to get beyond the disability rhetoric in dementia to critical analysis of how well concepts from disability really fit with the experiences of people with dementia.

2.1.6 Reflections

All three of the social perspectives, or lenses, inform this study of the communication of older people with dementia in residential care settings. Viewing dementia through the lens of person centred care highlights the importance of the interpersonal relationships of people with dementia to their well being and makes a clear argument for the need for further research into

care settings where the personhood of people with dementia is undermined every day (e.g. Kitwood, 1997). This approach also points to the importance of researching the experiences of people with dementia in care, so that the services might be improved (e.g. Allan, 2001). Finally, dementia care perspectives highlight the important role of the caring context in determining the well being and communication of people with dementia. It stops short, however, of providing a frame through which to analyse context outside of caring environments.

Viewing dementia through the critical gerontology and disability lenses highlights the influence of structural and cultural factors on both the way dementia is viewed and the experiences of people with dementia. Both perspectives highlight the importance of researching the experience of people with dementia themselves to address the 'othering' perpetuated by biomedical accounts of dementia. Furthermore, the perspectives stress the need to examine the experience of dementia in relation to wider socio-cultural processes. Finally, the disability perspective highlights the need to include people with dementia themselves in the research process, an issue which will be addressed in detail in chapter three of the thesis.

Before finishing this review of theoretical perspectives on dementia, it is interesting to reflect on the perspectives missing from the field as well as what is there. I would argue that two key perspectives of relevance to this study are missing. First, although I have called this section 'theoretical perspectives on

dementia', there is a striking absence of theory in the field, in particular sociological theory, and with a few notable exceptions, dementia researchers have used theoretical perspectives from other fields with little critical reflection or appraisal. Secondly, implicit in all three perspectives is recognition of the marginalisation and exclusion that older people with dementia face, in particular those living in care. There has, however, been no explicit theorisation of this vital aspect of the experiences of older people with dementia and little attempt to examine the experience of dementia in relation to broader social structures and cultural processes. This study is an attempt to address some of these gaps in understanding of dementia. First, however, empirical research on the experience of people with dementia is reviewed.

2.2 Empirical research on the experience of dementia

Over the past 20 years there has been a growing body of empirical research on the experience of dementia. Biomedical perspectives and quantitative approaches initially dominated the field with researchers seeking to reduce and generalise the experience of dementia. More recently, however, researchers have sought to understand the experience of dementia as lived by people with dementia themselves. This section reviews the research in this area, specifically as it relates to three aspects of experience of pertinence to this study, communication, self and being an older person with dementia living in an institution.

2.2.1 The communicative experiences of people with dementia

The ways in which the communication of people with dementia has been understood have largely mirrored understandings of dementia more generally. Much of the early research on the communication of people with dementia stemmed from a biomedical perspective and sought to identify the communicative deficits associated with the condition. Research examining the communication of older people with dementia, often in the context of neuro-psychological examination, found that they suffered from a plethora of communication problems. These included: flat and shortened speech; confused speech; repetitive questioning; difficulty finding words and names; losing track of speech; inappropriate subject changes; reduced positive emotional expression; faulty linguistic reasoning and reduced comprehension (Alpert et al, 1990; Bayles and Tomoeda, 1991; Bourgeois, 1991; Magai et al, 1996; Mentis et al, 1995; Quayhagen and Quayhagen, 1996; Whitehouse et al, 1997; Whitehouse, 1999). These findings were reinforced by research in institutional care settings. Observational studies revealed that older people with dementia in these settings engaged in little interaction, spending much of their days sitting doing nothing (Bowie and Mountain, 1993; Ward et al, 1992).

This body of research prompted a very pessimistic view of the communicative abilities of people with dementia, leading Bourgeois (1991) to conclude 'by the late stages of the disease, mutism, echolalia and bizarre nonsensical utterances may be the only product of communicative attempts' (1991:831). More recent research, however, has shown that the particular methods used to

gather these data exacerbated the communication problems people with dementia experienced, by testing them out of context, and were insensitive to many communication skills. Thus qualitative observation research during neuropsychological examinations revealed not only what a threatening context this is, but also that the older people with dementia being assessed engaged in a number of strategies to manage this context, reflecting their communicative abilities (Saunders, 1998b). Similarly research in institutional care settings has shown that, although interaction may be infrequent and thus may not be detected by systematic, time sampled observation studies, older residents with dementia do engage in pockets of rich and meaningful communication, highlighting their agency and communicative competence (Hubbard et al, 2003).

Examination of communication through a dementia care perspective, however, has led to a more positive perception of the communicative abilities of people with dementia. Research examining communication naturalistically and in detail, adopting a broad understanding of what constituted communication, including non verbal as well as verbal communicative behaviours, found that people with even very advanced dementia could indeed communicate (Norberg et al, 1986). This research highlighted the importance of context, relationship and appropriate stimuli to invoking communication with people with most advanced dementia and highlighted the heterogeneity of the communicative styles and preferences of people with dementia. Furthermore, research from this perspective theorised the central role of communication and shared

experiences to people with dementia's sense of personhood (Kitwood, 1993), integrity (Athlin and Norberg, 1987), and quality of life. Kitwood (1997) highlighted the ways in which both social isolation and negative or disparaging interactions threatened personhood and argued that through good communication, carers might support the personhood of people with dementia and in turn slow the progression of the disease. These insights prompted the development of a large body of research exploring how carers might support communication and be supported themselves to do this through specific interventions and by the caring regime.

A large body of qualitative interview and observation research explored the role of professional carers in facilitating communication with people with dementia. This work stressed the role of carers in compensating for the communication problems experienced by those with dementia and proposed a model for how this may be achieved (Athlin and Norberg, 1987). The model stressed the therapeutic use of the self of the carer in the context of the environment, organisation and the philosophy of care, as being central to promoting interaction. They also identified five key concepts underpinning interaction, synchrony; clarity of cues; sensitivity; interpretation and responsiveness. Interview studies with carers provided support to this model, and carers working with people with more advanced dementia identified the importance of providing 'motherly care' and acknowledged that this entailed using the self, something that required great effort with less favoured residents (Haggstrom et al, 1998; Hellner and Norberg, 1994; Rundquist and Severinsson, 1999). Berg et al

(1998) described how this use of self meant that nursing work was not only affected by the outside world, but that nurses reported that their work affected their lives outside the ward. Expert carers also highlighted philosophies of care that promoted communication. These included treating residents like respected partners (Haggstrom et al, 1998) and using empathy and identifying with the person cared for, in particular the roles they once had in society (Hellner and Norberg, 1994).

Observation studies showed the importance of clarity of cues to communication and that when carers and people with dementia had no common language to convey verbal cues, much less interaction occurred (Ekman et al, 1993; 1994). The importance of sensitivity in facilitating interactions was also stressed (Kitwood, 1997; Runquist and Severninsson, 1999). Carers were urged to be aware of the attempts of the person with dementia to communicate and to look beyond so called 'problem behaviour' to the meanings being conveyed (Kitwood, 1997). Finally research addressed the problem of interpretation. Hallberg and Norberg (1990) showed carers video recorded examples of 'problem behaviours' and asked care staff to interpret them. Carers were able to give an interpretation of the behaviours, but were unable to say how they did this and could not identify the behaviours that their interpretation was based on. This research highlighted the importance of context to interpretation, a finding supported by research using video which showed that researchers were better at interpreting the communication of people with advanced dementia when they

watched a whole interaction as opposed to a specific communicative behaviour (Jansson et al, 1992).

Research examining the ways in which carers could facilitate the communication of people with dementia was supported by research into a range of interventions to improve communication. Interventions described included: touch (e.g. Kramer and Gibson, 1991; Norberg et al, 1986; Snyder et al, 1995); music (e.g. Clair, 1996; Groene, 1993; Morrison, 1997); object presentation (Norberg et al, 1986; Witucki and Twibell, 1997); art (e.g. Craig, 2002; Killick and Allan, 2000; Shore, 1997; Wald, 1983); dance (Crichton, 1997; Palo-Bengtsson and Ekman, 1997); walking (Freidman and Tappen, 1991) and conversation classes (Santo Pietro and Boczko, 1998). These interventions were all found to be useful with at least some people with dementia, however the importance of matching the intervention to the person concerned was stressed (Morrison, 1997). The therapist was identified as key to the success of the intervention, possessing many of the same qualities as identified by studies of carers as being important to their everyday interactions with people with dementia (Perrin, 1998). As Magliocco notes 'the value (of therapeutic activities) comes from the shared experience and not necessarily the activity itself' (1997:145). Killick and Allan (2001) built on many of these ideas, above all stressing the need for care staff engaged in either communicative interventions, or everyday interactions to reflect on their own communication as well as that of the person with dementia they are communicating with.

Research into communication and dementia stemming from person centred and integrity promoting approaches to care has been useful in both highlighting the depersonalisation of older people with dementia at an interpersonal level and in providing a frame for carers to follow to address these processes. These moves have, however, been distinctly conservative, with communication continued to be conceptualised in terms of the medical model, and people with dementia conceptualised as the dependent recipients of care. Furthermore this research sheds little light on the ways in which people with dementia themselves manage their communication.

Insights into the communicative experiences of people with dementia themselves comes from three distinct research areas. These are: research looking specifically at the communicative experiences and abilities of people with dementia themselves; research seeking to elicit the perspectives and 'voice' of people with dementia; and research examining the experience of dementia, in particular in relation to self and identity. These studies, all adopting qualitative methodologies have revealed much about the communication of people with dementia.

Observation of the communication of older people with dementia revealed their use and interpretation of non verbal as well as verbal communicative behaviours, to fulfil a range of roles. These included replacing words that had been forgotten and to refer to things that were better left unsaid, for example the need to go to the toilet (Hubbard et al, 2002; Sabat, 2001). Analysis of the

communication of people with dementia living in a nursing home using an interactionist frame found they used everyday forms and conventions of communication such as turn taking, responding to social cues, using ritual courtesy and taking roles (McColgan, 2001). Furthermore a number of studies have highlighted the use by people with dementia of narrative forms of communication and metaphors (Cheston, 1996; Crisp, 1995; Killick and Allan, 2001; Mills, 2003; Saunders, 1998a).

Research that has sought to elicit the perspectives of people with dementia has also revealed much about the communicative abilities of people with dementia. In the context of one to one interviews, people with dementia have talked about their experiences of receiving a diagnosis of dementia (Pratt and Wilkinson, 2000); their experiences in day care (Reid et al, 2001); their quality of life (Dabbs, 1999); their powerlessness in services and relationships (Proctor, 2001); their experiences and management of pain (Cook, 2001); and about themselves and their experiences more generally (Killick and Allan, 2001; Phinney, 1998; Sabat, 2001; Seman, 2002; Snyder, 1999). The need for the researcher to have good listening skills and be prepared to interpret what the person with dementia is saying has been identified as vital to the success of the interview (Dabbs, 1999). People with dementia have also demonstrated their many communicative skills through their active participation in research, including writing accounts of the research process (McKillop, 2002 and Robertson, 2002). Others have written accounts of their experience of having dementia (e.g. Davies, 1989).

Much of the research looking at the communication of people with dementia themselves has highlighted their skilled use of communicative devices to assert a positive self identity, in particular in response to a potentially threatening situation (Crisp, 1995; Sabat and Harre, 1992; Saunders, 1998a, 1998b). As already cited, in the context of a neuro-psychological interview, people with dementia used humour to 'save face' and developed complex cognitive, experiential, emotional and comparative accounts as well as accounts of their ability and attention to justify their inability to answer the questions posed, positioning themselves as 'normal' (Saunders, 1998a, 1998b). Similarly Crisp (1995) argues that the supposedly confabulatory stories her mother told were narratives serving many purposes including: reaffirming positive self identity; getting to know others; and making sense of life in order to face death. Thus the stories her mother told followed a pattern, with a start, middle and end, starred her mother, who generally had to overcome some difficulty to the acclaim of a critical onlooker. She goes onto cite Gerbaud, writing in French, 'Narcissism is the lifebuoy of an identity that is drowning' (1988: 138). This research highlights the important role of the interaction partner in the interaction, not just to listen to the stories, but also in supporting, or otherwise the presentation of self of the person with dementia (Crisp, 1995; Sabat and Harre, 1992).

More recent research on the communication of people with dementia has highlighted both the many communicative abilities of this population, and the importance of communication and interaction for maintaining a positive self

identity. This body of research is limited, however, as although it reveals much about how the communication of people with dementia is supported or constrained by carers and researchers, little is known about how people with dementia manage their own communication, in particular in relation to other older people with dementia. Furthermore, this literature says much about the depersonalisation of older people with dementia at an interpersonal level, but largely ignores the influence of cultural and structural factors on their communication. These issues are addressed specifically in this research study.

2.2.2 People with dementia's experiences of self

Given the closely interwoven nature of communication, self and experience, it is unsurprising that trends in understanding communication and dementia closely mirror changing understandings of self in dementia. Understanding of the self in dementia has been somewhat vague with researchers drawing on a number of different concepts when referring broadly to what Charon (1994) describes as a person's core being, encapsulating both their personality and life history. These include personhood (e.g. Kitwood, 1997); self (e.g. Sabat, 2001); sense of self (e.g. Crisp, 1995) and identity (e.g. Orona, 1990). These terms have been used somewhat interchangeably by people working in the field, however in this study I use the term self-identity to refer to a person's experience and presentation of himself or herself. Just as the medical model questioned the ability of people with dementia to communicate, so did it question the presence of a very sense of self for people with dementia. The self and experiences of people with dementia were conceptualised entirely in terms of those who cared for them.

Interviews with carers revealed the extent to which they felt they had 'lost' the person they were caring for, making the task of caring more burdensome (Orona, 1990).

The development of person centred care worked to counter these negative conceptualisations of the experience of identity of older people with dementia (Kitwood, 1993). In particular, Kitwood (1993) promoted a conceptualisation of personhood that privileged emotional and lived experience, especially that shared with others, as opposed to memory and consciousness. Jenkins and Price (1996) built on these insights and challenged the applicability of dualist philosophical perspectives on personhood and the self to dementia. They critiqued these perspectives for placing too much emphasis on the importance of abstract reasoning, self concept and notions of rights, duties and obligations. Instead they highlighted the dynamic and constructed nature of self and personhood for people with dementia and posited that there is a role for nurses in helping families keep the feeling that the personhood of the person with dementia is alive.

The extent to which the self of people with dementia is socially constructed has also been highlighted by Sabat and Harre (1992) and Sabat (2001). Drawing on the work of Goffman (1959), they argue that people with dementia have many selves constructed in relation to others, and that different selves are dominant in different contexts (Sabat and Harre, 1992). Thus as Sabat and Harre conceptualise it, selfhood (a person's experience of their self) is evidenced, not

through abstract concepts of self awareness, but by positioning the self in relation to others, time and place. They use the example of a man with dementia, JK, who identified two different selves in interviews, one as a research participant and the other as a burden on his family. Sabat (2001) develops these ideas in his later book to highlight three selves in dementia: self 1 based on static personal attributes, such as being a son; self 2 based on shifting attributes, such as being a student; and self 3, the self we present to others. He describes in detail the ways in which the language of people with dementia emphasises their sense of self through both perlocutory and interlocutory force. This research also highlights the importance of other in the construction of self, and they describe the case of a woman with dementia, IK whose nurturing self was only evidenced in the day care setting away from her overbearing husband. This finding led them to conclude that selves are not lost in dementia, merely threatened (Sabat and Harre, 1992).

Further research has highlighted the ways in which others have worked to maintain the self-identity of people with dementia. Identity refers to the way a person is viewed, or is identified in relation to the rest of society, and can be manipulated by both the person themselves, or those around them (Biggs, 1999). Vittoria (1998, 1999) describes a nursing home where the staff used what she termed a language of openings to support the positive self-identity of the residents. Staff were careful in their use of metaphors, for example in describing a resident who was losing capacity, used a horizontal metaphor of 'taking a turn', as opposed to 'going downhill'. Vittoria highlighted the

importance of these strategies both for preserving the power of the resident and enabling the staff to actively construct and make sense of their world.

These observations have been supported by research in an Israeli nursing home ward. Gollander and Raz (1996) describe the way in which other residents reconstructed the behaviour of two male residents with difficult behaviours as understandable and acceptable in light of their prestigious personal biographies. Therefore when the former scholar stared into space, he was described as being a great thinker and when the former pioneer tried to escape from the ward his behaviour was interpreted as an understandable search for free land and wide open spaces. Families and care staff supported these presentations, by reminding the resident and those around them of past achievements and in one case even dressing a resident in a white coat to reinforce their identity as a doctor. Other residents in the ward, however, without these well-known biographies, still had their more consistent presentation of self deconstructed by staff and 'normal' residents. Furthermore 'normal' residents identified with some bitterness the advantages afforded those residents with dementia, in terms of their absolved responsibility both for their day to day behaviour and for their ill health. The extent to which this construction of people with dementia is beneficial, however is questioned by Golander and Raz (1996). They argue that this construction of dementia obscures people with dementia's 'idiosyncratic intentions' and operates as a means of normative control. As with the staff in Vittoria's study (1998, 1999), reconstructing the identities of the residents is a means to making staff worlds

more meaningful, whilst denying the agency of the person with dementia themselves.

This research highlights both the extent to which people with dementia are active agents in their social worlds, and do indeed have a sense of self. The research also highlights the extent to which communication and selfhood are interwoven, with communication being a key means by which people with dementia assert self and through which their selfhood is threatened. However, the research also shows that self is influenced by experiences, including of having dementia, and the broader context in which those experiences occur. In the following section research into people with dementia's experiences of care is reviewed.

2.2.3 The experiences of people with dementia living in institutional care

There has been a large body of research examining the provision of care for people with dementia in institutions. This research has highlighted the problematic nature of care, and in particular the poor quality of life experienced by many older people in care settings (e.g. Bredin et al, 1995; Kitwood, 1997; Peace et al, 1997). Research into the experience of living in a care setting highlighted the difficulties faced by people moving into care settings (Chatterji, 1998; Gubrium, 1975; Reed, 1999). Interviews with residents who have recently moved into care revealed the traumatic nature of this experience, and their need to have their self identities supported (Peace et al, 1997; Reed, 1999). Indeed Gubrium (1975) highlights the extent to which the resident's sense of

self is at stake, with residents feeling abandoned, let down and cheated by relatives. Thus institutionalisation involves a period of grieving for lost ties and the 'familiar trivia of everyday life' (Gubrium, 1975:87). An ethnographic account of one man's move into care illustrates the range of emotions experienced, with Mr R moving from uncertainty as to how to behave, to anger when he realised he had been left by his wife, and finally acceptance when he realised he had to stay (Chatterji, 1998). Older residents have been found to have a clear view about what constitutes a legitimate reason for moving to a care home, with having a relative who refuses to care being an illegitimate reason (Wilcocks, et al 1987).

Research into life in institutional care settings has universally documented how little there is for residents to do (Godlove et al, 1982; Nolan et al, 1995; Ward et al, 1992). Continuous observation of residents in one care setting found that they spent half their days doing nothing (Bowie and Mountain, 1993). Examination of life in care settings reveals many barriers to social interaction, for example noise, lack of privacy, seating arrangements and chaos (McColgan, 2001). Furthermore the success of interventions in place to stimulate the older residents, such as social dancing is contingent on others around them acting in context appropriate ways (Palo-Bengtsson and Ekman, 1997). Ethnographic research in institutional care settings has, however, highlighted the ways in which residents create meaningful occupation in settings that at first glance seem devoid of social activity (Gubrium, 1975; Hubbard et al, 2003; McColgan, 2001; Paterniti, 2000). Gubrium's (1975), observations in a residential home,

Murray Manor, revealed that passing time was a key occupation for the residents involving wandering, dozing, chatting, and social watching, and was governed by a number of routines and ceremonials. This finding is supported by recent research carried out in a number of institutional care settings which found that residents engaged in rich and varied social interaction including humour and flirting. (Hubbard et al, 2003).

It is unsurprising then that residents report their interactions with other residents to be important to them (Reed, 1999) and many residents report having friendships within the home (McColgan, 2001; McKee et al, 1999). However, not all contact with other residents has been found to be positive. Gubrium, (1975) found that lots of the resident's time was spent working to avoid, as well as maintain social ties. Residents have been found to distance themselves from those who are frail or confused as either they didn't want to be thought to have dementia or feared they might get it (Reed, 1999). Similarly Hazan described a nursing home in Israel where 'At the top of the ladder were the active and healthy in mind and body, while at the bottom were the physically and mentally frail.' (1994:38). Thus it would seem that the social ties residents have with other residents influence their self-identity.

Research in institutions has shown that they are meaningful places and people within them actively make meaning. Gubrium's (1975) account of a residential care home highlighted the meaningful nature of the home for both staff and residents. People were defined by others in terms of their role in the home, and

residents were further defined by their abilities, with residents separated spatially depending on the extent to which they could care for themselves. Furthermore staff have been found to make meaningful residents in terms of the kinds of work they entail (Paterniti, 2000). Paterniti describes how residents with impressive personal biographies or who were less disabled were able to overcome this construction and assert their own self-identity.

Residents and staff have also been found to make meaningful and draw meaning from space as well as people. Observations in a nursing home revealed that residents colonised chairs and spaces, guarding them with sticks and handbags (Harris and Lipman, 1980). Staff played a role in this, instructing people where to sit and eat. Gubrium (1975) also described how cliques in Murray Manor defended certain spaces, whilst other spaces were stigmatised, such as 'upstairs' where the more dependent residents lived. Thus spaces in Murray Manor were defined as public or private, depending on the number of people who had ownership of them, and who was in them. These researchers highlight that not everybody had equal control over the meanings associated with spaces, with the more powerful people ultimately determining the ways in which a certain space was interacted with.

Reed-Danahay (2001) has challenged the conceptualisation of nursing home as home. She highlighted the importance of taking on board the meanings the residents themselves make of the nursing homes they are in when making decisions regarding how to furnish and organise the institution. Reed-Danahay

(2001) argues that by calling the nursing home a home, residents are left feeling dislocated, as it is not their home, prompting them to respond to it in different ways, e.g. as a place of work that they try and leave at the end of the day. By acknowledging what she has termed the 'non-place' nature of nursing homes she argues we might approach their management in a more locating way, making them comfortable, as opposed to home like. These insights build on the work of Jackson (1995) who argued that being 'at home' is not necessary about place, but is more about an existential sense of control and connectedness, the way we feel when what we say or do seems to matter.

Despite the impoverished nature of many caring environments, this research reveals that residents make meaning from their experiences and many live rich and varied social lives in the settings. Interactions and relationships with other residents are central to this end and association with other residents may bolster or impinge on the self-identity of a resident. Nonetheless it is clear that the experience of institutionalisation is one that impacts negatively on self-identity, but that many residents are active in managing that impact.

2.2.4 Reflections

The empirical research on communication, self and living in a care home has shown how communication, sense of self and experiences of institutionalisation are interwoven. The research reveals that although people with dementia do have communication problems, these problems are exacerbated by threats to their self-identity and impoverished social contexts. However, this review also

highlights the importance of the communication of the residents in asserting a positive self-identity and making meaningful the context in which they find themselves. The review of this research also highlights the importance of researching the experiences of people with dementia themselves as opposed to their carers. It is interesting to note that despite the recognition of the importance of non-verbal communication to people with dementia, to date, understanding of the experiences of people with dementia and their sense of self has tended to be grounded in their verbal communication. Thus this research ignores the ways in which people use non-verbal communication to assert a sense of self and make meaningful themselves in their social contexts.

It is clear from this review of research that any understanding of the communication of people with dementia needs to be grounded in an understanding of their experiences, self-identity and context. In the following section the context in which older people with dementia live is examined in detail.

2.3 Society, institutionalisation and the marginalisation and exclusion of older people with dementia.

Review of research in sections 2.1 and 2.2 revealed that to date, dementia has been examined relatively atheoretically with little consideration of the broader context in which older people with dementia live. Despite the widespread implicit recognition within the field of dementia of the marginalisation and exclusion of older people with dementia in care, relatively little attention has

been paid to understanding the processes by which this occurs. A review of research more broadly, however, enables the construction of an account of the ways in which older people with dementia in care are marginalised and excluded at societal and institutional levels and is presented in this section. Before embarking on this review of the literature it is important to clarify the ways in which the terms marginalisation and exclusion are used in this study. Marginalisation has been defined as the process of positioning people or issues either on the edge of society or as of little importance (Valentine, 1990). Social exclusion has been defined as 'the dynamic process of being shut out, fully or partially, from any of the social, economic, political and cultural systems which determine the social integration of a person in society. Social exclusion may, therefore, be seen as the denial (or non-realisation) of the civil, political and social rights of citizenship.' (Walker, 1997:8). The terms marginalisation and social exclusion pervade research, policy and practice and are used in a plethora of different ways most commonly to refer to economic, structural and cultural processes operating at a population level. However, processes of marginalisation and exclusion occur not only at a population level, but are also reproduced through the interactions of an individual with the world around them (Denzin, 1992; Plummer, 2001). Therefore it is important to explore not only the impact of particular structures and processes on populations as a whole, be they lone parents, asylum seekers, or older people with dementia living in care, but also on the individuals whose day to day lives are shaped by those structures and processes.

In this study the terms marginalisation and exclusion are used to refer to processes operating at a population and interpersonal level, reflecting the emphasis of the research on the subjective experiences of older people with dementia. Research from the fields of ageing, disability, dementia and institutionalisation informing this endeavour is reviewed in three sections. In the first section, understandings of the ways in which older people with dementia are marginalised and excluded by society are considered. Then research into processes of institutionalisation and the marginalisation and exclusion of people living in care homes is reviewed. Finally theoretical and empirical research exploring the impact of these processes on the individuals is examined.

2.3.1 Society and the marginalisation and exclusion of older people with dementia

The role of modern society in the marginalisation and social exclusion of older people and those with disabilities has been widely noted (Featherstone and Wernick, 1995; Hughes, 2002; Laws, 1997; Post, 1995). Modern culture is founded on the enlightenment ideals of progress and rationality and as such values and rewards citizens who aid progress through their contribution to production and who conform to a generalisable ideal (Bauman, 1997). However, the extent to which people who cannot, or choose not to conform to these ideals are 'othered' by society has been widely reported (Fine, 1994; Oliver, 1990). Thus many women, children, older people, people who are ill or impaired, and those who belong to an ethnic or sexual minority group are marginalised and excluded by modern society (Barnes et al, 1999).

Two key roads to marginalisation and social exclusion, created by modernity, can be identified. Firstly, the complex web of social structures developed by modern society to serve the needs of the population and maintain social order can be seen to meet the needs of the 'ideal' citizen at the cost of 'others' in society leading to their marginalisation and exclusion (O'Brien and Penna, 1998). People with impairments (including older people) are excluded from society by social policies that deny them access to mainstream housing, education, public buildings, transport and employment opportunities (Barnes et al, 1999). Furthermore, capitalist economies, through the development of welfare benefits, have excluded older and disabled people from the labour market systematically denying them access to equal resources (Estes, 1979; Kennedy and Minkler, 1998; Phillipson, 1982; Quando and Reid, 1999; Walker, 1999). In these ways structures in society have excessively disabled a large population of older and impaired people not only making the experiences of ageing and impairment more problematic for the individuals concerned, but also making them dependent on society to meet their basic needs (Estes, 1979; Oliver, 1990).

A key response to this 'structured dependency' (Townsend, 1981: 1) has been the development of extensive industries to assess who is and is not part of 'normal' society and to provide care for those who are excluded (Oliver, 1990). In capitalist societies, the nature of this provision is influenced by market factors and the drive to make profit (Estes, 1979; Oliver, 1990; Robertson, 1990). Thus

the response by society to the needs of older and disabled people can be seen to be driven by the industrio-medico complex as opposed to consideration of how their experiences may best be accommodated by society (Estes et al, 2001). Furthermore, Estes et al (2001) have stressed the influence of the for profit sector in determining policy to meet the needs of dependent older people in institutions, as opposed to their own homes.

The second road to the marginalisation and exclusion of 'others' in modern society is through the cultural signs, symbols and discourses that serve to legitimise the status of some kinds of people, whilst delegitimising others (Plummer, 2001). In these ways 'others' are marginalised and excluded in their day to day interactions with the world, through representations and language used in both the public and private sphere. Laws (1997) sought to understand how space and place influence identity formation in old age. She describes how space and place can be used to create positive identities for older people to 'buy into', (e.g. retirement communities), but can also devalue older people (e.g. residential and nursing homes). The lack of a positive or productive role has been highlighted as a key way in which older people are marginalised in society (Hazan, 1994; Matthews, 1979). Hughes develops these ideas, arguing that people with disabilities were defined by modern society 'as the antithesis of cleanliness, rationality and order' (2002: 575) prompting their confinement in institutions (along with older, ill and deviant people) to preserve social order. Drawing on the work of both Foucault (1967) and Bauman (1997), Hughes

(2002) described how modern culture led to the ultimate exclusion of those defined as the 'other', that is institutionalisation.

The fear with which modern and post modern societies look on old age, dementia, disability and death has been widely noted (Elias, 1985; Featherstone and Wernick, 1995; Hughes, 2002; Moran, 2001). This fear has led to the marginalisation and exclusion of older, disabled, and dying people from the community as well as from the collective consciousness. Fetherstone and Hepworth (1991) described how negative discourses around the ageing body hide the inner selves of the inhabitants of such bodies, a process that they describe as the 'mask of ageing'. Furthermore, Elias has described the 'tacit isolation of the ageing and the dying from the community of the living' (1985: 2) and Featherstone and Wernick (1995) argue that death has been reclaimed as a violent condition of younger people, tied to AIDS, cancer and violent crime. Post (1995) highlights the ways in which the 'hyper-cognitive' nature of society has led to the demonising of dementia, and McColgan et al (2000) illustrate the ways in which failing cognition was described as a disaster by the press reporting on the death of celebrated author Iris Murdoch from dementia. Moran extends this argument in his review of three narratives of dementia highlighting how the terminal nature of dementia renders it 'unspeakable' (2001: 259). Harper (1997) develops these insights, identifying the loss of control of the body as central to the embodiment of older people. Pointing out that embodiment is something experienced by women, people from minority ethic groups and those with disabilities throughout their life course, she surmises that if (masculine)

bodily control were not such an important aspect of adulthood, then old age would be less stigmatised.

A key response to this fear of ageing, death, disability and dementia has been the move to focus on 'healthy ageing' and in particular on ways in which older people themselves might help themselves to remain healthy into old age (WHO, 2002). This movement has captured the imagination of gerontologists who have explored how older people might maintain health and quality of life into old age through interventions such as exercise (Paulson, 2003) and drama groups (Old Spice Drama Group, 2003). Although clearly of great benefit to those who have the resources and health to participate in these activities, the healthy ageing agenda places the responsibility for wellbeing firmly with the older adult and tends to sideline systemic barriers to good health. Furthermore, little consideration has been given to how those who are very frail, dying or who have conditions not amenable to rehabilitation, such as dementia, can be accommodated in this drive to healthy ageing.

Over the past twenty years society has changed dramatically, to the extent that it has been said that modern society has been eclipsed by a post modern one (O'Brien and Penna, 1998). Globalisation, development of the media and telecommunications and decentralisation, have prompted the development of new more reflexive societies where history, knowledge and power are all questioned (Bentz and Shapiro, 1998). These changes, and in particular to the media and information technology, have led to a shift in the ways in which

people are represented, which has allowed individuals and groups greater freedom to define themselves, legitimising their interests in society (Holstein and Gubrium, 2001). Furthermore, Hughes (2002: 578) has argued that these changes have gone hand in hand with a change to a 'post-modern world view' where a wide range of values and experiences are tolerated. These changes have implications for people on the margins of society, who, it is argued, have more opportunities to be included in society. Gilleard and Higgs (2000) have highlighted the possibilities for older people to shape and determine their social identities through their leisure and consumer choices, and Featherstone (1995) has highlighted the potential of new virtual communities in the inclusion of older people.

Many authors have, however, been cautious about the possibilities for inclusion of older and disabled people in post modern culture (Laws, 1997). As Hughes (2002) sums up

> The new criterion for inclusion in post-modern culture is the ability and willingness to consume. Unless disabled people have the resources and wherewithal to participate in cultures of consumption they will continue to be marginalised. (Hughes, 2002:580)

These arguments have also been applied to older people (Featherstone and Wernick (1995), as Laws says 'not all older people have access to the resources to allow them to choose which of the identities they wish to wear' (1997: 99). Furthermore, examination of wealthy older people's housing choices reveals that there is no appealing consumption choice that accommodates

death, dependence and disability (Tulle-Winton, 1999). Thus older people living with dementia are yet to benefit from opportunities for inclusion and self invention that post modern society has afforded other marginal groups, such as 'third agers' and people from minority sexual groups (Gilleard and Higgs, 2000; Plummer, 2001).

The research reviewed in this section has highlighted the extent to which older people with dementia are marginalised and excluded by society, and denied access to either material or cultural resources. As Hughes (2002) highlights, the ultimate consequence of this marginalisation and exclusion is institutionalisation. In the following section, understandings of the institutional context in which older people with dementia live are reviewed.

2.3.2 The institutional context: processes of marginalisation and exclusion

The institutionalisation of older and disabled people and individuals from other marginal groups has been widely condemned for perpetuating the marginalisation and exclusion they face (e.g. Foucault, 1977; Goffman, 1961; Townsend, 1962). Townsend (1981) argued that the very presence of institutional care settings influences social values and attitudes to the care of older people, making institutionalisation a legitimate option. In this way institutionalisation perpetuates the marginalisation of older people culturally making it more likely that they will be excluded from society physically. The extent to which a move to an institutional setting exacerbates individual experience of exclusion has been widely reported. Research in residential care

settings has found that few residents received regular visits from friends and family (Gubrium, 1975; Peace et al, 1997). The remote location of many institutional care settings has been found to exacerbate this situation with residents neither able to travel back to their communities by public transport, nor to receive visits from friends and family dependent on public transport (Reed et al, 1998). The physical separation of people in institutions not only leads to their individual experience of exclusion, but also renders older and disabled people invisible, perpetuating their marginalised status in society as a whole (Barnes et al, 1999). Oldman and Quilgars (1999), however, argue that older people in institutions are often no more excluded than frail older people in the community who are confined to their own homes.

Critiques of institutionalisation have also highlighted the extent to which institutions are depersonalising and controlling, marginalising the individual wishes, needs and sense of self of the residents (Foucault, 1977; Goffman, 1961; Gubrium, 1975; Paterniti, 2000). Goffman (1961) described the ways in which institutions are self serving, working to the good of the institution, as opposed to the people in them. Total institutions, as he termed them, forced staff and inmates into a position of opposition, with both sides defining each other in terms of their institutional meanings, rarely seeing the person behind the institutional role. These findings have been supported by the work of Gubrium (1975) whose ethnography of life in a nursing home for older people highlighted the ways in which the regime depersonalised the residents, defining them by their location and the types of care they required as opposed to who

they are. In a later paper Gubrium and Holstein (1999b: 537) extended this analysis to describe how meanings in nursing homes shaped the ways the very bodies of residents were described, being linked with decrepitude and decline. They summarised this process saying 'We age bodily, in other words, as much because our bodies are discursively anchored by a particular institution, as because our bodies grow old.'

Foucault (1977) examined the ways, what he termed 'austere institutions', sought power and control over the 'inmates', marginalising their individual needs. He described how institutions exerted their power over the inmates in diffuse ways, a key means being to ensure the surveillance of the inmates at all times. Foucault argued that through both observation and the examination and documentation of inmates bodies and personal biographies, institutions imposed their 'gaze' on the inmates, asserting power and control. He highlighted the transformative potential of this gaze, and described the ways in which processes of documentation brought the personal biography of the inmate under inspection, for example transforming a person who has committed a criminal act into a delinquent. Research studies into institutional care settings for older people have found these same processes in operation. McColgan's (2001) ethnographic study of a dementia unit in a nursing home revealed the extent to which the unit was designed to ensure the surveillance of the residents and reflected that, as a researcher, she too was subject to the institutional 'gaze'. Paterniti (2000), described the ways in which assessment of

the medical needs of the residents became incorporated into their biographies, shaping staffs treatment of that resident as a whole.

Since the later part of the 20th century there has been a move away from institutionalisation to care in the community (Tinker, 1997). This has meant that some older and disabled people who once were totally excluded from society in institutions are now either supported in their own homes, or in community based special housing (Peace and Holland, 2002). For people still in institutions there have been moves to make the experience of institutionalisation less depersonalising, with residents viewed as consumers of care and institutional care settings encouraged to involve them in decision making in the home (Scottish Executive, 2002). Research in residential care settings, however, has revealed that in reality there were few channels for the views of residents to be heard (Abbott et al, 2000). The consequence of this is that the prospect of residential care is still faced with fear and dread by many older people (Peace and Holland, 2002). Thus despite the efforts to improve care settings for older people, institutionalisation still serves to further the marginalisation and exclusion faced by people already marginalised and excluded by society. In the following section the impact of this marginalisation and exclusion on the individual is examined.

2.3.3 Experiencing social exclusion and marginalisation, the impact on self identity

A key concept that has been used to understand the influence of marginalisation and exclusion on self identity is stigma. Matthews (1979) highlighted the applicability of Goffman's concept of stigma to older people. Goffman identified stigma as being 'an attribute which is deeply discrediting' (1961:3). He highlighted the relational and contextual nature of the concept, arguing: 'An attribute that stigmatises one type of possessor can confirm the usualness of another and therefore is neither creditable nor discreditable as a thing in itself'. Thus stigma is something borne by people who are identified by others as differentiating from the 'normal'. Matthews (1979) interviewed older people and described the ways in which they were forced to face their ageing and stigma in encounters with both others and their self. She described the ways in which they dealt with this stigma, for example by differentiating themselves from other old people; not revealing their age; constructing oldness as being distinct from chronological age; bringing in outside sources who corroborated their lack of oldness; and avoiding threatening situations. In these ways the older women constructed themselves as people first and older people second. However, Matthew's research found that negotiating their self-identity in encounters with the self was more difficult. Discourse was found to be the key means at the disposal of the older women to assert a positive identity as someone different from other old women.

Central to Goffman's (1961) account of stigma was recognition of the difficulties and uncertainty stigmatised people faced in their interactions with others. He highlighted the difficulties faced on both sides with stigmatised people worrying that every aspect of their behaviour will be misconstrued as being down to the stigmatised quality, and people not possessing the stigma worrying that they were being too demanding or patronising. Goffman argued that stigmatised people gained many benefits from interacting with others who possessed the same stigmatised attribute, in particular where they joined together to represent their concerns to society collectively. However, he also conceded that encountering others with the same stigmatised condition forced people to face their own stigma and therefore could be difficult, in particular for people who acquired the stigmatised condition later in life. This was supported by the findings of Matthews highlighting the tension older women experienced interacting with others of the same age. Thus, this conceptualisation of stigma highlights the ways in which being positioned as marginal and excluded fundamentally influences the self-identity of the person and permeates all of their interactions.

More recent research in the fields of ageing and disability has suggested a more complicated relationship between experiences of marginalisation and exclusion and self-identity. Watson (2002) interviewed people with disabilities who were able to construct a positive self identity despite their disability, which they viewed as being just one facet of many that influenced their lives and the way they viewed themselves. Reeve (2002), drawing on the work of Foucault.

described some of the ways in which disabled people both experienced and resisted psycho-emotional processes of exclusion. She argued that disabled people are subjectified through processes of surveillance, but are also able to act to resist the impact of this on their self-identity. Similarly, gerontologists have argued that older people experience ageing as a mask, which instead of fundamentally shaping their self-identity, acts to hide who the person is beneath (Featherstone and Hepworth, 1990). Biggs (1999) argued that this mask could be beneficial to the older person, mediating their interactions with others and therefore protecting their self-identity from potential threat or upset. However, Featherstone and Hepworth (1991) conceptualised the impact of managing this process somewhat differently, arguing that 'The individual struggle to maintain a balance between the external stereotypes of age-appropriate behaviour and the subjective experience of the self requires considerable energy, tenacity and other resources.' (1991:378).

The work of Foucault has been particularly influential in understanding the experiences of people who are marginalised and excluded. In particular, researchers have drawn on his work on power and subjectivity to shed light on the ways in which older and disabled people are marginalised and excluded and may resist these processes of exclusion (Hughes, 2002; Katz, 1996; Reeve, 2002; Twigg, 2003). Foucault argued that power was not exerted by The Law, but through multiple and complex practices of governmentality (Rabinow, 1984). Through his analyses of aspects of society such as penology, medicine, and psychiatry, Foucault described the ways in which technologies of

power dominated and objectified people through their day-to-day interactions with the world leading to the marginalisation and exclusion of people defined as mad, sick and deviant. He identified three ways in which individuals came to be depersonalised, what he termed 'modes of objectification of the subject' (Rabinow, 1984: 7). He highlighted the ways in which people were objectified by: dividing practices, such as being institutionalised; through classifying discourses, such as the medicalisation of ageing and dementia; and finally through self subjectification, the efforts of people to understand themselves as mediated by authority figures (Rabinow, 1984). In his essay Technologies of the Self, Foucault (2001) described the ways in which people since Greek and Roman times have been urged to look to their selves, guided by the cultural and or religious dictums pervading at the time. In these ways human subjects become the agents of their subjectification by society, internalising their oppression which becomes totally bound with their sense of self. The drive to 'healthy ageing' is a good example of such a technique of self-subjectification.

A central concept in Foucault's work was that of resistance. His fluid, inter-subjective conceptualisation of power led him to conclude that power and resistance go hand in hand (Twigg, 2003). Specifically he argued that individuals could turn round processes of self-subjectification to become agents of their resistance (Foucault, 2001). Knowledge of subjectification, he argued was critical to resistance as it was only when people knew they were subjectified that they could know to resist it. This notion will be explored in more detail in chapter six.

Research reviewed in this section has shown that belonging to a marginalised and excluded group impacts on self-identity. Whether or not old age, dementia and institutionalisation are experienced as stigma or as a mask, these aspects of experience are clearly vital to understanding the communication of older people with dementia living in residential care and are explored in more detail in chapter six.

2.3.4 Reflections

Research reviewed in this section has highlighted how difficult the social context is in which older people with dementia in residential care live. They face a triple jeopardy: being marginalised and excluded on the basis of their age; dementia; and residence in institutional care. Therefore it is vital that research on communication and dementia considers these important aspects of their experience. This study draws on a number of theoretical perspectives to inform the exploration of the ways in which living with dementia in a care home influences the communication of older people. These are reviewed in the next chapter.

2.4 Conclusion

Review of the research on dementia has shown that to date our understanding of dementia is limited. The field has been dominated by biomedical conceptualisations of dementia and relatively little research has sought to

understand the experiences of older people with dementia themselves. Instead, much of our understanding of the experience of dementia comes from those who have cared for or interacted with people with dementia. This research has sought to understand dementia within a very limited social context. Although the influence of broader social structures and cultural processes is recognised in the rhetoric of the 'social model of dementia' there has been no serious attempt to understand the experience of dementia in relation to this broader context.

These ways of understanding dementia in general are reflected in understanding of the communication of older people with dementia specifically. This has been seen primarily in terms of the communicative deficits of people with dementia and how carers and caring environments might overcome them. To date, understanding of the communication of older people with dementia from a non-biomedical perspective has been very atheoretical with only passing reference made to mainstream theories of communication.

This chapter has sought to extend understanding of dementia and the communication of people with dementia by reviewing theoretical and empirical literature informing understanding of the experiences of older people with dementia themselves in context. This research has shown the extent to which having dementia is a problematic experience, in particular for those living in care homes who face communication problems, threats to self identity and live in depersonalising regimes. Review of the social structures and cultural processes influencing the experience of dementia highlighted the extent to

which older people with dementia living in care are marginalised and excluded. This occurs at societal and institutional levels on the basis of their age, dementia and residence in an institutional care setting. Furthermore, examination of theoretical research into stigma, the mask of ageing and processes of subjectification has revealed the impact of these experiences on communication and self-identity.

The aims and research questions guiding this study reflect the imperative to understand the communication of older people with dementia themselves in context. Thus the aim of the study is to not to explore how older people with dementia living in residential care communicate, but to understand how these aspects of their experience contextualise their interactions and influence their communication. The first three research questions locate this understanding firmly in the experiences of the individuals with dementia in this study. The study examines the communication of the older residents with dementia in relation to the meanings they make of their lives with dementia in a care home, how these meanings impact on their self-identity, self-determinacy and social networks, and how they respond to these meanings through their communication. In this way, the study sets the scene for addressing the final and most important research question, how might we understand the communication of older people with dementia living in residential care.

In the following two chapters the theoretical and methodological approaches taken to address this aim and research questions are outlined and the methods used described.

Chapter 3

Understanding communication in context: theoretical and methodological approaches

3.0 Overview

The review of the research literature in the fields of dementia, ageing, disability and institutionalisation presented in chapter two, highlighted the need for research that seeks to understand the communication of older people with dementia in a residential care home to:

- be grounded in the experiences of older people with dementia themselves

- examine those experiences in relation to the social contexts in which they live

- include visual as well as verbal aspects of experience

- include people with dementia in the research process

In this chapter, the theoretical and methodological approaches used to operationalise these imperatives are presented and the implications of adopting these approaches for the methods of data collection, analysis and overall thesis are discussed. In the first section, the theoretical perspectives informing the approach to understanding the communication of the older residents with

dementia are described. The opportunities and limitations presented by adopting these perspectives for researching dementia are examined in detail.

In the second section, the three key aspects of the methodology guiding the research are outlined. These are: the use of an ethnographic approach; the inclusion of the older residents in the research; and the use of video. The implications of the methodological approach for understanding the communication of older residents with dementia and the research design are explored in detail.

3.1 Theoretical approach to the research

This study seeks to understand the subjective experiences of older people with dementia living in residential care in relation to the social context and in particular social structures in which they live. As reviewed in section 2.3, much of the previous research that sought to bridge the gap between individuals and structures in this way drew on post modern perspectives. The ulitity of such an approach to understanding the experience of ageing in particular has been stressed (Jamieson and Victor, 1997; Katz, 1996). Researchers working from this perspective argue that there is no one way to know the world (e.g. Laws, 1997; Ray, 1996). Thus, post-modern approaches to research: privilege the perspectives of the research participants (e.g. Fine, 1994); reflect on the role of the researcher in the construction of knowledge (e.g. Sanger, 1996); recognise that research data is co-constructed with research participants (e.g. Guba and Lincoln, 1994); refute the generalisability of research findings (Denzin and

Lincoln, 1994) and highlight the constructed nature of the research text (e.g. Atkinson and Hamersley, 1994).

Although useful to understanding the experiences of older residents with dementia generally, this perspective does not provide a frame for examining the communication of older residents with dementia specifically. A symbolic interactionist approach is drawn on to understand the communication of the older residents with dementia in this study. Symbolic interactionism is grounded in a relativist ontology. The approach views the world as being constructed through the interactions of people within it and therefore consisting of multiple constructed realities. Communication is central to the symbolic interactionist approach to understanding the world as it examines the subjective experiences of the research participants in relation to the context in which they live out their daily lives (Prus, 1996). Furthermore, a review of the literature on the older people with dementia found that this approach has usefully informed understanding of the communication of people with dementia in relation to their sense of self (Sabat and Harre, 1992) and their experiences in institutional care settings (McColgan, 2001; Vittoria, 1999).

There has been some debate as to the appropriateness of incorporating post-modern and interactionist perspectives to understand human life. Prus (1996) argues vehemently against the trend within ethnography to combine interactionist and post-modernist positions. Arguing against an extreme post modern position, he pointed out the inconsistency of combining an approach

that privileges empirical data (interactionism) with one that questions all knowledge. Furthermore, he critiques proponents of post modernism for intellectual sloppiness, arguing that they pick and choose from interactionist and post modern perspectives. A key focus of Prus's criticism is the work of Denzin (1989; 1992) who merged critical, interactionist and post modern approaches to form his own approach interpretive interactionism. Denzin (1992:56) critiqued the 'astructural bias' of symbolic interactionism and argued for an interactionist social science that explicitly deals with social structures.

A comprehensive review of the epistemological underpinnings and relative merits of the different perspectives and the debates is beyond the scope of the thesis. Instead, over the following pages the symbolic interactionist perspective is reviewed and the ways in which it is used in this study outlined. In particular, the opportunities and limitations provided by the approach for understanding the communication of people with dementia are described and the ways in which both critical and post-modern insights inform the approach to the research highlighted. The implications for the research findings of adopting such an approach are presented.

3.1.1 The symbolic interactionist perspective

Symbolic interactionism is a school of sociological / social psychological thought that examines how social actors assemble meanings, define themselves and their situations and examines how these meanings and definitions are modified and transformed (Plummer, 1991). One of the first people to elucidate this perspective was George Herbert Mead (1934) who saw social action as the

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starting point from which to examine mind, self and society. Social action constitutes acts carried out by a social actor, that is someone who is acting in consideration of others or indeed the self (Charon, 1994). Mead (1934) made the distinction between mind and self and highlighted the ways in which humans, as opposed to animals, engaged in internal conversations, interacting both with themselves and with consideration of their self. Meltzer (1967) highlighted how these internal conversations, by enabling the social actor to take on the role of the 'generalised other', are central to the interpretation of meaning and also to decisions regarding how to act on the basis of these meanings.

Central to the symbolic interactionist perspective, and in particular the work of Blumer (1969), is the importance of meaning. Blumer who played an important role in defining and shaping the discipline identified three key assumptions on which the perspective rests (Craib, 1992; Prus, 1996; Rock, 2001). The first of these is that people act towards social objects on the basis of the meanings they have for them (Blumer, 1969:3). A social object is any entity that a social actor interprets symbolically and may not be a material object at all. Cultures, institutions, spaces, policies and relationships may all be conceptualised as social objects, along with the people who interpret them (Charon, 1994). The consequence of this assumption is that social actors do not respond to a material reality, but to their interpretation of that reality (Rock, 2001). Thus this assumption grounds understanding of the communication of a social actor in

the meanings they make of themselves and the world around them and highlights the agency of the social actor.

The second key assumption identified by Blumer (1969), was that meanings arise in the process of interaction between people. As Blumer articulated: 'The meaning of a thing for a person grows out of the ways in which other persons act toward the person with regard to the thing. Their actions operate to define the thing for the person' (1969:4) This means that the sense of self of the social actor as well as their understanding of the world around is defined socially, through their interactions with others in the world (Charon, 1994; Rock, 2001). This assumption highlights the importance of broader social context to understanding the meanings a person makes of themselves and the world. The final assumption outlined by Blumer (1969:5) was that people create, modify and negotiate meanings through a process of interpretation. This assumption predicates that different social actors will make different meanings of the same thing, and it applies to the meanings a social actor makes of their self as much as to the meanings they make of others and the world around (Berger and Luckmann, 1966). Thus meanings and sense of self are not stable entities but are constantly negotiated through interactions and in different social encounters.

The symbolic interactionist perspective as elucidated by Blumer highlights the agency of the social actor who through action and interaction with the world is engaged in a constant process of meaning making, testing out and negotiating

these meanings through their subsequent interactions. However, missing from his account of symbolic interactionism is an understanding of the actual process of interaction. He does not outline what individual social actors bring to their processes of meaning making and how that influences the meanings they make and the ways in which they respond to those meanings. Drawing on the work of Mead (1934), Blumer did make a small contribution to developing such an understanding, identifying the 'goals' of any interaction. He argued that the interpretations that an actor made were influenced by what they sought to achieve in the context of any interaction, i.e. by their goals. Blumer had little to say about what informed these goals of interaction. Goffman (1959), however, highlighted the fundamental importance of preserving self-identity to determining the goals of interaction and decisions made regarding the course of future action. He conceptualised social interaction as a performance, with the social actor always acting in consideration of the impression they are giving to others and actively working to manage that impression. For Goffman, social interaction and self-identity were inexorably intertwined.

The importance of the perspectives of the social actor in understanding social interaction has been highlighted (Charon, 1994; Prus, 1996; Shibutani, 1961). Shibutani (1961) described the ways in which social actors develop perspectives on themselves and the world that guide the meanings they make in interactions and the ways in which they respond to those meanings. He conceptualised social actors as existing within a social world, which is experienced as a set of reference points guiding the meanings made in any

interaction. This social world is accessed through interaction with the media, school, workplace etc. and changes over the course of the lifetime of the social actor. In this way, Shibutani (1961) argued, social, cultural and historical processes influence the interpretation of the social actor of meaning, limiting their agency. Prus extended this understanding of perspectives writing 'perspectives also encompass people's definitions of rules, norms, prevailing practices, lines of authority, consensual understandings, and other 'rules of thumb' that people develop to provide guidance of a generalised nature' (1996:151).

Charon (1994) brought these insights together and presented a model for understanding social interaction from a symbolic interactionist perspective. He conceptualised social interaction as consisting of processes of interpretation, decision-making, and response. He described the process whereby a social actor encounters a meaning, interprets that meaning, makes a decision about the impact of the meaning on their goals of interaction and responds accordingly. According to this model, the perspectives, social worlds, context, reference groups, self and goals of the social actor influence every stage of this process, which occurs within a stream of action. Thus any one communicative act, such as a gesture, request or demand is both the culmination of a process of interpretation, decision making and goal setting and the start of a new cycle of interpretation, decision making and goal setting. Stream of action is the term Charon (1994) uses to describe the path of interaction, which he conceptualised as meandering forwards. Charon (1994) described how the direction of the

stream changed in response to the things that the social actors bring themselves to the interaction, such as their perspectives and goals, but also in response to what is happening between the social actors in the interaction and within the broader context for the interaction.

The research on symbolic interactionism reviewed so far has been primarily concerned with defining the field of enquiry and seeking to understand how social actors do social life. There is, however, a body of research that has used an interactionist frame to understand how specific groups of people in context make sense of themselves and their experiences and act in the world. This research has highlighted the role of context and processes of social exclusion and marginalisation in shaping the experiences of social actors. Denzin (1992) highlighted that the meanings that people make of any given social object are influenced by what they do (projects) and why (practices) which are in turn influenced by the context they find themselves in. Furthermore, research looking at the experiences of older people has revealed that the meanings of some social objects, such as people, constructs, buildings and spaces are harder to negotiate than others (Harris and Lipman, 1980). Thus social actors live in unequal relations of power with others that influence whose meanings prevail (Plummer, 2001). This was exemplified in the research of Golander and Raz (1996) described in section 2.2, that described the power of staff and more able residents to shape the self identities of less able residents.

3.1.2 Opportunities and limitations for understanding the communication of older residents with dementia

The symbolic interactionist perspective as elucidated by Blumer (1969) and developed, in particular by Charon (1994), has profound implications for taking forward understanding of the communication of older people with dementia. Previous research on the communication of people with dementia has focused on the deficits they experience and the role of others in overcoming them. The symbolic interactionist approach, however, examines the communication of the person with dementia him or herself purely in relation to that person's own experiences. The approach makes no value judgements about what are correct or incorrect ways of communicating, but simply seeks to record and interpret what is going on from the perspective of the person with dementia. In this way, drawing on the symbolic interactionist approach side steps the issue of cognition and provides a frame to understand the communication of people with dementia that places them in the centre. The approach highlights the agency of the older residents with dementia and awakens us to the notion that different social actors might make different meanings of the same thing. Furthermore, the approach reveals the ways in which the meanings a person makes of themselves and the world around are influenced by the social context in which they find themselves and the interactions in which they engage. In this way the approach provides a frame to examine communication in relation to self, experience and context.

The utility of the symbolic interactionist approach for understanding the communication of older people with dementia in residential care is, however, limited in a number of ways. Firstly, despite the fundamental place of communication in this perspective, there has been little detailed examination of the processes of communication from this perspective, with the notable exception of Goffman (1959). Communication has been dealt with primarily as the key to understanding social life and society as opposed to the focus of the investigations. Secondly, the empirical data on the experiences of older people with dementia living in residential care, presented in section 2.2, contests the notion that society is symbolic interaction. That is to say that this research clearly shows that the experiences of older people with dementia in residential care are governed by a range of structures and processes that are experienced as real by older people with dementia and are not simply constructed through social interaction. However, by privileging the experiences of the person with dementia him or herself and examining the meanings he or she makes of the structures and processes with which he or she interacts, the symbolic interactionist approach does provide a frame through which to examine their experiences of powerlessness, marginalisation and exclusion. In this way the symbolic interactionist approach has lots in common with post modern approaches that critically examine the social, historical and geographical situation of discourses and assumptions central to our understanding old age, as well as the relationships that reproduce them (Laws, 1997; Ray, 1996).

A final limitation of the symbolic interactionist perspective, as framed by Blumer (1969), for understanding the communication of older people with dementia in residential care is the aim of scientific validity. Blumer (1969:50) challenged social scientists to empirically test the validity of the premises of symbolic interactionism by examining social life according to its principals. However, this ambition is inconsistent with the relativist ontology of the perspective and the conceptualisation of meaning as grounded in the meaning maker, as opposed to the social object, and constructed and negotiated through social interaction. More recently, however, researchers working in a symbolic interactionist frame have embraced a more relativist understanding of the research process itself, highlighting the influence of the researcher in shaping the data collected (e.g. Prus, 1996; Rock, 2001). Conceptualising the research process as symbolic interaction frees the researcher to respond to the perspective as a set of constructs that can be applied to aid an understanding of the experiences of a group of older people with dementia in residential care. This has implications for the product of the research, as it can no longer claim to be the explanation of why things are, but is itself a social object, and one of many possible conceptualisations of the issue at hand.

This way of understanding the research process then corresponds much more closely with the post modern approach to research outlined in section 3.1.1 (See chapters in Denzin and Lincoln, 1994 for a detailed overview of the approach). Viewing the research process as symbolic interaction means firstly that the researcher, as the social actor making meaning of the phenomenon

under study, is firmly situated in the research. Just as the meanings a research participant make of their interactions in the world are influenced by their perspectives, reference groups, goals etc., so are the interpretations of the researcher influenced by their own perspectives, reference groups, goals etc. This approach conceptualises the data collection as occurring in a stream of action, influencing and being influenced by the social actor, or experience under study, leading to the co-construction of the data by the researcher and research participant. This means that the data gathered are the result of a synergy between a particular socially situated researcher and a particular socially situated research participant, both of whom bring to the research encounter a set of perspectives, goals and understandings that profoundly shape that research encounter and the data gathered. As already highlighted, this has implications for the product of the research (this thesis) which must be seen as one of many possible constructions and interpretations of the topic under study and therefore cannot claim to be generalisable. Denzin and Lincoln (1994) argue that social scientists need to leave behind notions of generablisability, validity and reliability and instead strive for rigor and utility. This rigor, they argued, stems from immersion into the participants lives and being reflective and explicit about the interpretations reached.

Adopting the theoretical frame for the research described above has a number of implications for the methodology. These are outlined in the next section.

3.1.3 Methodological implications

The reinterpretation of the interactionist frame used in this study to understand the experiences of the older residents with dementia has a number of implications for the methodology. Most importantly it means that to understand the communication of the older residents with dementia, the researcher needs to interpret the behaviours and communication observed (Blumer, 1969). To do this, the researcher must immerse him or herself in the lives of the participants and engage intersubjectively with them (Prus, 1996). It is only through gaining this kind of intimate familiarity with the research participants that the researcher can understand enough of their context and perspectives to interpret their interactions (Denzin, 1992; Prus, 1996; Rock, 2001). This kind of interpretation also demands that the researcher engage with micro level aspects of the situation under study (Blumer, 1969).

Central to the interactionist perspective is recognition of the importance of the empirical world. This means that it is impossible for a researcher to know or be able to predict what they will find until they go into the field (Blumer, 1969). This demands that the research methods and questions are exploratory and allowed to develop with the research (Atkinson and Hammersley, 1994). Furthermore, if the research is not to actively disempower the research participants, it is vital that not only are their experiences at the centre of the research, but that they are involved in the research process (e.g. Fine, 1994; Oliver, 1992; Wilkinson, 2001). These methodological implications call for the researcher to be engaged with the research participants in the contexts in which they live and to engage in

a constant process of interpretation and reflection on the ideas emerging from the data. Furthermore the researcher must be willing to reflect on the methods used to gather the research data and their relationship with the research participants. These considerations have led many researchers working from interactionist and post modern positions to adopt an ethnographic methodology (e.g. Denzin, 1989; Prus, 1996; Rock, 2001). This approach is also used in this study, alongside an inclusive, video methodology. These three aspects of the methodology are considered in detail in the following section.

3.2 Methodological approach

The methodological approach to the study is governed both by the four imperatives generated from review of research on dementia outlined at the start of the chapter and by the theoretical approach described in section 3.1. The four imperatives are: that the research be grounded in the experiences of the older people with dementia themselves; that their experiences are examined in relation to the social contexts in which they live; that visual as well as verbal aspects of experience are included in the research; and that the participants with dementia themselves are included in the research process. Consideration of these issues led to the development of an ethnographic, inclusive, video methodology to understand the communication of the older residents with dementia. Over the following sections each aspect of this methodology will be considered in turn. The reasons for adopting the methodology are outlined, and the implications for taking such an approach for the data collection and analysis are discussed.

3.2.1 Ethnography

Ethnography is an approach used to understand the social worlds of individuals or groups of people through sustained engagement in those social worlds. The approach stemmed from anthropology and was originally used to research remote communities. However more recently has been used to research idiosyncratic groups or disadvantaged sections of society (Denzin and Lincoln, 1994). Atkinson et al (2001) described ethnographic research as 'firmly rooted in the first hand exploration of research settings' (2001:5) and argued that central to ethnography is a sense of social exploration and protracted investigation. This means that ethnography works on the understanding that knowledge of participants lives is held in the field, not the library (Rock, 2001). Through participant observation, informant interviews and documentary analysis, ethnographers collect detailed unstructured data about the experiences of their research participants in relation to the contexts in which they occur (Atkinson and Hammersley, 1994). Ethnographers seek to understand the social lives of the people under study in relation to the meanings they make in their everyday lives (Gubrium, 1975). Furthermore, the unstructured nature of the data collected enables new theoretical ideas to emerge from the data (Baszanger and Dodier, 1997; May, 1993). In addition ethnographic methods allow the voice of the participants to be heard and therefore have been popular amongst researchers committed to emancipatory research (Agar, 1996).

Ethnography has been a popular approach amongst researchers seeking to understand the experiences of older people, including those with dementia in institutional care settings. Ethnographers have sought to understand the culture of caring institutions from the perspective of care assistants (Lee Treweek, 1995) and from the perspective of the older residents (Gubrium, 1975; McColgan, 2001; Reed-Danahay, 2001). They have examined the experience of entering a care home (Chatterji, 1998) and examined how staff and other residents construct each other in the settings (Golander and Raz, 1996; Patterni, 2000; Vittoria, 1999). Thus ethnography has been successfully used to understand many aspects of the lives of older people in institutional care settings, including their communication (McColgan, 2000).

Researchers who have described the process of doing ethnography have highlighted the messiness of the enterprise. Geertz (1993) described ethnography as 'an elaborate venture in thick description' (1973:6) and referred to 'piled up structures of inference and implication through which an ethnographer is constantly trying to pick his way' (1993:7). Rock (2001) in his description of the natural history of an ethnography highlighted the fear that ethnographers face, entering the field not knowing what they are looking for, and urged prospective ethnographers to resist the temptation to head back to the library in the early stages of field work. Rock (2001) went on to highlight how dependent ethnographers are on serendipity and luck and finding the right informants. This is something that has been reiterated in many accounts of doing ethnography. Lofland and Lofland (1995) highlight the importance of

building good relationships in the field, and Agar (1996) described how relationships are influenced by a gamut of factors including institutional affiliation and role in the setting. Indeed Barley (1983) in his account of ethnographic work in Africa highlighted the central role gifts of alcohol played to developing relationships with his informants.

The key ethnographic method used in this study is that of participant observation. Participant observation stems from the Chicago school of ethnography and involves immersion in the day to day lives of the research participants (May, 1993). Lofland and Lofland (1995) defined it as 'the process in which the investigator establishes and sustains a many sided and relatively long term relationship with a human association in its natural setting for the purpose of developing a scientific understanding of that association' (1995:18). Gold (1969) identified four roles of a participant observer. These are: complete participant, a covert observer fully engaged in the activities under study; participant as observer, an overt observer forming relationships with the participants seeking to engage them in conversation about their life as well as observe it; observer as participant, an overt observer engaging briefly with the world of the participant; and complete observer, an overt observer who is removed from the activity under study. The ethics of entering the field as a complete participant have come to be widely questioned (Lofland and Lofland, 1995), and participant as observer is generally accepted as the preferred role of the ethnographer (May, 1993) and is the one adopted in this study. However Roth (1970) highlighted that no matter how open a researcher is, participant

observation will always be a partially hidden enterprise, as the researcher does not know what they are looking for when they enter the setting and therefore cannot communicate that overtly to the participants.

The complex and messy nature of doing ethnography has many implications for analysis of the data. Geertz (1993) described analysis as 'sorting out the structures of significance and working out their social ground and import' (1993:9). This process is by necessity iterative and starts in the field (May, 1993). Thus the ethnographic researcher checks out their emerging theories as their data collection progresses, being willing to shift the research questions accordingly (Prus, 1996). The aim of analysis is to start with detailed interpretations of micro level events and to move to substantive theory through comparative analysis of cases (May, 1993). Lofland and Lofland (1995) presented a frame for this process, calling researchers to look at their data first in terms of meanings and then move to examining it in relation to practices, then roles, then groups, then organisations and finally to social worlds.

This understanding of the process of data analysis fits well with an inclusive approach to research, which demands that the research responds to the experiences and perspectives of the research participants themselves. This aspect of the methodological approach is examined in the following section.

3.2.2 Including people with dementia in the research process

Including the experiences of the participants in the research has been identified as essential to broadening understanding of social life, and the importance of allowing the experiences of the participants to frame the research has already been discussed. There are, however, additional pressing ethical and political reasons for including participants in research. Fine (1994) has identified the ways in which the exclusion of the experiences of the participants from research can perpetuate their 'othering' by the research process. She describes how traditional colonial ethnographers presented the 'others' they were studying as homogenous groups, in particular by their conventions of extrapolating the activities of the prime male to the rest of the individuals in the society. She argues that these ways of presenting others reinforce a view of the group under study as a homogenous population, in need of our benign help and support. Framing the research in relation to the experiences of the participants themselves, however, reveals the heterogeneity and agency of the population being studied.

These understandings of the dangers of 'othering' both reflect, and have been embraced by researchers examining the experiences of disabled people. Indeed, much research on disability is carried out by disabled researchers themselves (e.g. Barnes, 2003; Oliver, 1992). Although there are debates in the literature of the supremacy of white, middle class, physically disabled male researchers, innovative methods are being used to ensure that the voices of diverse groups of disabled people shape the future of disability studies

(Walmsley and Downer, 1997). For example, Anya Souza (with Paul Ramcharan) presented her experiences of having Downs Syndrome in a book chapter (Souza and Ramcharan, 1997).

These and other such arguments as to the importance of including participants in the research have been articulated by many researchers. Feminist, non-disablist and anti-racist researchers have all highlighted the need to include the research participants in the research. Until recently, however, people with dementia have been left out of these moves, deemed incapable of even consenting to participation in the research. Therefore, even researchers examining the subjective experience of dementia made no mention of including the participants in the research (e.g. Gubrium, 1991; Gubrium and Holstein, 1999b; Lyman, 1988; Vittoria, 1996). The growing popularity of the social model of dementia, has however, prompted researchers to take the issue of including people with dementia in research more seriously, to seek ways of circumnavigating their impairments to enable their inclusion in the research, and to reflect on this in their research accounts.

When examining the issue of including people with dementia in research it is important to be clear what is meant by inclusion. Wilkinson (2003) has conceptualised inclusive research as operating along a continuum. At one end of the continuum (and most common in the field of dementia) is research that includes people with dementia at the most basic of levels, that is by including their experiences in the research, informing them about the research project

and seeking their consent for participation (e.g. Pratt and Wilkinson, 2000; Proctor, 2001; Reid, 2001). Much of this research has focused on hearing the views of people with dementia on the services they receive. Dabbs (1999), Proctor (2001) and Reid (2001) all spoke to service users about their experiences of the services they received. Pratt and Wilkinson (2000) asked people with dementia to reflect on their experiences of receiving a diagnosis of dementia and Allan (2001) in a piece of pedagogic research explored the ways in which the views of people with dementia on services could be elicited. However researchers have also sought the interpretations of people with dementia on their non verbal communication (Hubbard et al, 2002); their perspectives on quality of life (Corner, 2002); legal issues (Mason, 2002) and pain (Cook, 2002).

Central to this research has been the issue of getting consent to involve the participants in the research project. A central tenet of medical ethics is that all research participants should give written informed consent for participation in the study (Medical Research Council, 2000). However, this is inherently problematic when researching the experiences of a population whose capacity to give informed consent is by definition impaired. Traditionally researchers overcame this problem by gaining written informed consent from a proxy for the person with dementia. This approach as well as having no legal standing, has been widely critiqued for disempowering the person with dementia (e.g. Dewing, 2002). Research with people with dementia has demonstrated that if research is explained clearly, many people with dementia can give consent to

take part (e.g. Cook, 2003; Mills, 2003). A number of techniques have been described that have been used successfully to make research understandable to people with dementia. These include using everyday language when talking about the research (Reid, 2001); providing easy to read consent materials with photographs of the researcher (Allan, 2001); asking about the research in the context of a relationship (Allan, 2001; Dewing, 2002; Reid, 2001); and seeking consent on an ongoing basis (Dewing, 2002; Hubbard et al, 2002). The move to seek ongoing consent from people with dementia, termed process consent, has been particularly useful in increasing their inclusion in the research (Dewing, 2002). Process consent does not rely on the research participant remembering about the study from one day to the next, and gives the participant the chance to reassess whether they want to take part in the study, having experienced what that involvement entails (Hubbard et al, 2002).

These approaches to gaining consent from people with dementia have turned the idea of informed consent on its head and have shown that by working with people with dementia they can be supported to make considered decisions about whether or not to participate. More recent research at the other end of the continuum of involvement has shown that people with dementia can make a far more substantial contribution to the research than merely consenting to take part. Gloria Sterin, who has dementia, has worked with Phyllis Braudy Harris to research the ways in which people with dementia preserve their sense of self. Sterin and Braudy Harris both interviewed people with dementia and jointly analysed and wrote up the research findings (Braudy Harris and Sterin, 1999).

Sterin, a retired academic, has also written in the Journal of Dementia about her experiences of dementia (Sterin, 2002).

The involvement of people with dementia in research in this way has been rare, requiring as it does a somewhat serendipitous meeting of minds and resources and is beyond the scope of this study. Conceptualising involvement as a continuum, however, allows the researcher to work in many different ways to move towards the emancipatory end of the continuum. This has two key implications for the ways in which the research is carried out. Firstly, it means that the researcher takes time to engage with the participants with dementia and to work with them to help them understand the study, so that they might input into the process. Secondly, the researcher must be prepared to loosen control over the research and let the research participants inform the methods used and questions asked. Thus an inclusive approach to the research fits well within an ethnographic methodology as outlined in section 3.2.1.

An inclusive, ethnographic methodology enables the experiences of the older residents with dementia to be examined in context and for them to be included in this research. Central to the research, however, is recognition of the need to research visual as well as verbal aspects of the communication of the older residents. Therefore the study uses a video methodology, which is described in the following section.

3.2.3 Using video

Recognition of the importance of non-verbal communication to understanding the communication of older people with dementia in residential care led to the decision to use video to access visual and non-verbal aspects of the research participants experiences. In so doing, the study builds on a relatively small tradition of visual research in the social sciences (Harper, 2001; Pink, 2001).

Video is a relatively under used tool in social science research (Prosser, 1998). Researchers seeking to understand visual aspects of social life have tended to use photography and have paid little attention to the potential of using video in the research process (Pink, 2001). Research that has used video, however, has revealed the many benefits of this methodology. Video recordings of social life allow non-verbal aspects of experience to be captured and create a permanent record of the experience that may be subjected to micro level analysis time and time again (Rosenstein, 2002). Furthermore, video enables those involved in the interaction recorded to reflect and comment on their behaviour (Caris-Verhallen et al, 1998; Sanders and Dabbs, 1992). In the field of dementia, video has been used successfully in both these ways to examine the responses of people with very advanced dementia and the perspectives of staff during caring interactions (Athlin et al, 1990; Kihlgren et al, 1996; Norberg et al, 1986; Phillips and Van Ort, 1993). This literature, however, has neither described in detail the ways in which the video was used nor reflected on the practical, epistemological or ethical issues raised by the use of video to observe the communication of people with dementia.

A key issue identified by researchers who have used video to examine social life is the extent to which the recording is a true and representative depiction of 'real life' (Prosser, 1998). The potential distorting influence of the video camera on the behaviour of the research participants has been widely reported (Heacock et al, 1996; Lomax and Casey, 1997; Rosenstein, 2002). Furthermore the influence of the person using the camera on the data collected has been highlighted (Roberts et al, 1996; Rosenstein, 2002). Pink (2001) highlighted how the video camera shapes the researcher's identity and influences the way they communicate with the research participants, pointing out that this influence will change in different situations and in different relationships. Thus the resulting recording can be seen to be both a social and technical constructed representation of the phenomena under investigation. This is unproblematic in the context of an interactionist, ethnographic approach that questions the extent to which a true and representative depiction of 'real life' is possible in any research, and embraces the influence of subjective aspects of the research relationship on the data collected. In this context, the distorting influence of the video camera becomes merely one more aspect of the research situation to reflect on. As Pink (2001) argues 'Reflexive ethnographic video makers need to be aware of how the camera and video footage become an element of the play between themselves and informants, and how these are interwoven into discourses and practices in the research context' (2001:80). Lomax and Casey (1997) demonstrate the possibilities for using the video recorded data itself to reflect on the influence of the camera in the construction of the research data.

In their study of midwife encounters, Lomax and Casey (1997) analysed the ways in which the new mothers responded to the camera, and found that this reflected the ways in which they differentiated between what they considered to be midwifery business from social aspects of the visit.

Lomax and Casey's (1997) research shows how video can enable researchers to reflect critically on the research process, which is essential to the development of new inclusive methodologies for people with dementia. Furthermore, the ubiquity of video in society makes it an ideal tool for involving people in research unfamiliar with traditional research methods. Video has been used successfully to disseminate the findings of a participatory project involving older women (Warren and Maltby, 2002) and as a medium for older people with dementia to document their life stories (Rose, 2000). The use of video has also enabled researchers to collaborate with their participants both in setting up the practical aspects of the recording (Lomax and Casey, 1997; Pink, 2001) and in playing back the recordings to the participants and seeking their perspectives on them (Pink, 2001). Hoskins (1993) however, found that playing videos back to her research participants some years after they were originally taken caused much upset and discomfort.

Using video in research raises a number of ethical issues above and beyond those encountered by researchers drawing on an ethnographic approach generally. In particular, the visual nature of the medium makes the research participants immediately identifiable and therefore the data must be handled

particularly carefully to ensure the anonymity of the participants. Furthermore, the visual nature of the data makes it incredibly powerful. A video, or even a still image of a person, includes a plethora of information that is not readily apparent from a textual description, or that may be easily edited out, and therefore can convey all kinds of information over and above that intended by the researcher. Video recording older research participants with dementia, in particular those who exhibit behaviours feared or disparaged by society, and showing these videos out of the context of the research setting leaves the participants vulnerable to ridicule and judgement.

Given the significance of these ethical issues, it is concerning that visual researchers have largely ignored the ethical implications of their work. Review of the Visual Studies journal reveals that visual sociologists regularly publish photos of people who are unaware they are being photographed for research, let alone giving consent to have their image used. Even researchers using video with people with dementia have not reflected on the ethical implications of their work, aside from my own contributions and those with my colleagues (Cook, 2002; Cook, 2003; Hubbard et al, 2003). Pink (2001) has, however, reflected on the ethics of a visual ethnographic approach to research and argues that by engaging collaboratively with the research participants in collecting and interpreting the data, researchers can negotiate issues of anonymity, ownership of the materials and empower the participants in the process.

The research reviewed clearly shows that video is a useful tool for researching experience and is amenable for use in an inclusive ethnographic methodology. The innovative nature of the methodology, however, demands that any researcher using video both reflects on its use and the implications for the data gathered. A detailed account of the success of the video methodology used in this study is presented in the following chapter.

3.3 Conclusion

This chapter outlined the theoretical and methodological approach used to understand the communication of the older people with dementia living in residential care in this study. The study draws broadly on a symbolic interactionist approach to understand communication. This approach is particularly useful for understanding the communication of older people with dementia as by focusing on the meanings the person makes through the interactions with the world around them, the approach highlights the agency and communicative abilities of the person with dementia. This is particularly important as, to date, research in this field has tended to focus on the communicative deficits people with dementia experience and how they may be overcome by carers. Instead, this study rejects the deficit model of dementia and seeks to understand the communication of people with dementia in relation to their self, experiences and the contexts in which they interact. In so doing, the study brings a theory of social life generally to understanding the experience of dementia specifically, and conceptualises the participants as social actors first, and people with dementia second.

Central to this study is recognition of the marginalised and excluded position of older people with dementia living in residential care. This recognition is reflected in the emphasis of the theoretical approach on understanding the communication of the participants in relation to the broader social context in which they live. The symbolic interactionist perspective is useful to this end as it provides an explicit frame through which to examine communication in context. However, the study also draws on critical and post modern approaches to understanding social life. Consideration of these perspectives led to the rejection, in this study, of the understanding that society is symbolic interaction and can be understood scientifically so central to the perspective as articulated by Blumer (1969). Instead the approach adopted in this study seeks to understand the meanings the older participants make of the structures and processes they encounter through their interactions with the world, and treats the research encounter as a symbolic interaction in the same way as any other interaction in the world.

The final limitation of the symbolic interactionist approach for understanding communication is that it focuses on examining communication to understand social life and does not provide a coherent frame for understanding the process of interaction. The approach highlights the importance of meaning making in interaction, but does not clearly explain how people make meaning and how context, life history, perspectives and experience influence the meanings made. A key task for this thesis is to provide a framework to understand how the

participants make meaning and how this is influenced by their experiences of living with dementia in a residential care home. This framework, must of necessity come from the data analysis and is outlined in chapters five, six, seven and eight.

This chapter also outlined the methodological approach adopted in this study. The choice of methodology is guided both by review of the literature and the theoretical approach presented in this chapter. The study adopts an ethnographic, inclusive, video methodology to understand both visual and verbal aspects of the communication of the older participants with dementia and to include them in this process. Such a methodology demands that the researcher engage intersubjectively with the research participants, reflects on the research relationships and process, and allows the methods and questions to shift over the course of the process in response to experiences in the field.

Ethnography has proven a popular methodology for researching the experiences of older people living in care homes, including people with dementia, and the issues involved in adopting such a methodology are relatively well understood. Similarly many researchers are now seeking to include people with dementia in research and there is an ongoing debate in the field about the ethics and politics of such research. Before this study, however, the use of video to understand the experiences of people with dementia within the context of an ethnographic, inclusive methodology was entirely undocumented. In the following chapter a reflexive account is provided of

success of this methodology alongside an account of the ways in which the methodology outlined in this chapter was put into practice to gather and analyse the research data presented in chapters five, six and seven.

Chapter 4

Research Methods

4.0 Overview

This study uses an ethnographic, inclusive, video methodology to explore how living with dementia in a residential care home influences the communication of older people. The aim of this chapter is to describe the methods used to gather and analyse the data for this study and to reflect on the success of the research process, as well as ethical and practical issues arising at each stage. The innovative nature of the research demanded that the topic was approached in an exploratory and grounded way and that the methods for researching the topic were allowed to develop with the study. At the time of data collection there was no textbook on researching the experiences of people with dementia and the development of the methodology was, by necessity, influenced by my experiences in the field.

The account of the methods presented in this chapter reflects the exploratory nature of the research methods and is presented in four main sections. In the first section a brief account of the development of the research methods is presented. Specifically the ways in which the proposed methods and research questions evolved over the course of the pre pilot and pilot phases of the study are described. In the second section, the setting in which the data were

collected is described in detail. In the third section the procedure used to gather and analyse the data is described and the ethical and practical issues arising during this time discussed. The final section reflects on the methods used and in particular the use of video. Particular ethical issues arising from the use of video are considered in detail and the ways in which these were addressed through the development of a multimedia CD-ROM, described.

4.1 Developing the research methods

As with many PhD studies, the methods used and indeed overall direction of the research shifted over the course of the four years. At the start of the study I had intended to use video to examine the ways in which carers facilitate the communication of older people with advanced dementia, in particular focusing on non verbal communication. Specifically I had planned to observe the communication of twelve people with advanced dementia using participant observation and video recording them in interactions with three carers they knew well. The innovative and exploratory nature of the research demanded that the research methods were piloted to explore the feasibility and acceptability of video as a data collection tool with these participants as well as to examine the ethical issues arising from using video in research. Therefore two pilot studies were carried out during the first six months of the research studentship.

The first pilot study was carried out in conjunction with Kate Allan and John Killick at the University of Stirling. This study sought to examine the feasibility

and acceptability of video to record one to one interactions with people with dementia, and to explore the potential of using video to reflect on those interactions. The second study was carried out in conjunction with Gill Hubbard, also at the University of Stirling, with the aim of comparing the interpretations of two researchers of the non-verbal communication of older people with dementia in naturalistic settings. This study was also used to pilot consent procedures with the older participants with dementia. The methodological and substantive findings of these studies are not described in detail here as they have been reported elsewhere (Cook and Hubbard, 2000; Cook, 2002; Hubbard et al, 2002, see Appendices A, B and C).

The two pilot studies were carried out concurrently over the course of May, June and July 2000 and were vital in shaping the research methods used and overall direction of the research. They established that the use of participant and video observation was feasible and that using video was surprisingly acceptable to the participants with and without dementia. They also identified a number of ethical issues and ways in which the consent procedures could be improved to include the participants in a more meaningful way. The pilot studies were particularly significant, however, in that they clearly challenged the deficit model of dementia. In particular, they highlighted the agency of the older residents with dementia and questioned the preconception that carers were central to facilitation of the communication of older people with even advanced dementia. Although care staff were observed to facilitate interactions, it was apparent that the participants with dementia themselves were taking a very

active role in managing their communication. Furthermore the pilot studies

showed that not only could the participants consent to the research process, if

not give written informed consent, but they could also contribute to the research

process itself. In particular, use of the video camera, by formalising and

providing a literal frame for the research, enabled participants to opt in and out

of the process, and therefore contribute to the collection and interpretation of

the data.

In light of these findings the overall aim of the study changed from examining

how carers facilitated communication, to exploring the communication of older

people with dementia themselves. As a result, the methodology also changed.

An ethnographic, inclusive approach was adopted, exploring the ways in which

a group of older people with dementia in one care setting negotiated their

interactions in context. Specifically, I wanted to examine the communication of a

group of older people with dementia in a setting where good quality care was

provided and that was generally supportive to their communication. Therefore

after seeking advice from colleagues at the Dementia Services Development

Centre I visited a number of day care and residential care settings in the local

area to find a suitable location for the main phase of the fieldwork. After visiting

a number of services, Elm View Residential Home for Older People[1] was

identified as an ideal location for the fieldwork. Not only was there a large

population of older people with dementia living in the home, but the residents

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[1] The names and distinguishing characteristics of the places and people referred to in this thesis
have been changed to ensure the anonymity of the research participants

engaged in lots of interaction in public spaces in the home and the manager was amenable to my desire to involve the older residents in the research process. In the following sections the research setting and research procedures are described in more detail.

4.2 A description of Elm View

Elm View was a local authority run residential home for up to 45 older people in a wealthy suburb in Scotland. Over the following sections a description of the home is presented.

4.2.1 Space in the home

The design of Elm View was typical of local authority homes built in the past twenty years. The building was set in a large garden on a quiet side street. At the entrance to the home was a conservatory area with chairs and tables in it. Through from the conservatory was the main foyer. This large, light and airy space was the hub of the home and from there all parts of the home could be seen or accessed. The Foyer was divided into two main sections. To the left was a large area furnished with low chairs and tables, a television and a radio, and on the right, an alcove with a high table and chairs. A day care group met in this space and resident meetings were also held here. Three offices were accessed from the front of this space, the administrator's office, the manager's office and the day care office. Towards the back of the space was a treatment room / hairdressing salon, two toilets and stairs to the upper floor of the home.

At the very back of the space was a lift to the first floor flats and the corridor leading to the kitchen and laundry.

The rooms of the residents were grouped into six flats, one at each of the four corners of the foyer on the ground floor and two upstairs at the back of the building. Each flat was colour coded for identification and decorated in a traditional style with floral wallpaper, a fireplace with a gas fire, curtains and a large dresser containing books and ornaments. The flats all contained a living area with armchairs, a television, two dining tables and chairs and a small kitchen in which the residents could make tea and snacks and from which the staff served the meals. The meals themselves were prepared in the main kitchen of the home and brought to each flat on a trolley. Residents all had their own rooms with a sink with six residents living in each flat. The residents shared two bathrooms per flat. Many residents had their own televisions and radios in their rooms and some had a telephone.

All the flats looked onto the garden, and the two downstairs flats at the back of the building had French windows and a patio onto the garden and the upstairs flats had small balconies. In good weather some of the organised activities of the home were held in the garden, however most activities were held in the craft room, a bright sunny room upstairs with space to seat up to fourteen people around a table.

4.2.2 Staff and care regime in the home

The home was managed by a team of three: one manager, Yvonne, and two deputy managers, Peter and Evelyn. Yvonne made most of the key decisions about running the home with Peter and Evelyn being responsible for implementing them when they were on duty. The manager, Yvonne, had moved to the home in the past three years and in this time had worked hard to implement a person centred approach to care. She was very tolerant of risk and encouraged the staff to allow the residents to find their own routines in the home. Thus residents were given a lot of choice in the home, getting up when they wanted and free to spend time in a range of spaces in the home. Some of the residents went out of the home as and when they pleased. The residents were also encouraged to have a say in how the home was run. A 'Residents' Meeting' was held every month for the residents to decide how the 'comfort fund' was spent on activities and non necessities for the home. Two of the residents also attended a citywide service users group for older people living in residential care. Yvonne was also very concerned with staff development and when I was doing fieldwork, several of the staff were working towards different kinds of social care and social work qualifications.

During every shift there were up to six care staff, who worked in teams of two, each pair covering two flats. The care workers provided personal care to the residents, served their meals, sorted out their laundry, made their beds and acted as key workers to a few of the residents. Meals were provided at set times every day and residents had a choice of two or three options. The menu

for the day was written on a chalkboard in the living area of each flat mid morning. Residents who wanted to eat in their rooms or at different times were accommodated to a degree, however mostly all residents ate together in the dining area of each flat. After the staff had made the beds, sorted out the laundry and served the meals, most of their time appeared to be taken up with their key worker responsibilities. These included: bathing the residents, helping them look after their clothes and other possessions, helping the residents keep in touch with family and friends, and either taking them out to buy, or buying for them new clothes and toiletries. However, key worker duties could be very varied and on the same day a key worker was observed to spend time painting the nails of one of her residents and then helping another resident sort out her mobile phone contract.

Aside from providing basic care, the home also provided residents with opportunities to engage in a number of social activities. Fiona, the activities leader ran a craft group in the morning and organised trips out every Wednesday. She also led a bowls group one afternoon a week and organised visiting entertainment, such as film shows and music. Many of the residents engaged enthusiastically in at least some of these activities. The home also had a visiting hairdresser, Mel, who came twice a week to cut their hair and was one of the few people the residents spent extended periods of time with on their own. This was something that male and female residents looked forward to and the hairdressing room was generally the liveliest place in the home when Mel was at work.

Less often seen by the residents were the maintenance, domestic and kitchen staff who only had passing contact with the residents. A few of the residents did know some of these staff members by name, in particular the bus driver.

4.2.3 Residents

Elm View provided a home for approximately forty five older residents at any one time, mostly female, who were in need of help with tasks of everyday living, or social care, but who did not need regular nursing care. At the time of starting fieldwork, many of the residents in the home were frail, but all were mobile with a walking aid. None of the residents were confined to their beds on a regular basis, though some chose to spend most of the day in bed. Mental health problems were prevalent amongst the residents, in particular dementia, which affected about half the residents in the home. Several of the residents were physically disabled and had been, before coming to the home. Three residents had learning disabilities, two of whom had spent their lives in hospital before moving to Elm View.

Despite the location of the home in an affluent suburb the residents varied greatly in terms of class and life history. Most of the residents were Scottish, many having lived in the same city all of their lives, though residents came from all over Britain and two from overseas, one woman, Lena, from Eastern Europe and the other, Maria, from Latin America. The residents varied greatly in terms of class and life experience. Maria, from Latin America, was the daughter of a

high ranking official and was used to having staff to clean and cook for her, whilst other residents like Rena had been 'in service' or like Nan, worked as cleaners themselves.

The low levels of care provided meant that many of the residents could have stayed in their own homes with appropriate support, however many of the residents had no close family or were separated from them. Some residents had never married or had children whilst others were widowed or estranged from their partners. Other residents had children that lived overseas or in England and were not at hand to help with their care. Relatively few of the residents received regular visitors, such as Mary Peters whose sisters visited every week, however a couple of the residents were able to go out to visit family and friends. One such resident was Tony, who because of his learning disability had a supporter that enabled him to go out to visit his brother regularly.

Over the time I spent in Elm View it was clear that the home was well managed and that all the staff worked hard to provide person centred care. Residents were free to move around the home as they chose and as a result there was generally a relaxed and happy atmosphere in the home. In this way Elm View constituted an excellent example of good practice in caring for older people and therefore provided a particularly interesting context within which to observe the communication of the older residents with dementia. The findings of this study inform understanding not only of how Elm View as an institution influences the communication of older people with dementia, but also how the communication

of older people with dementia is both threatened and supported by a model of care that is currently accepted as best practice.

In the following section the ways in which the data was collected in this setting and analysed are described.

4.3 Research design and procedure

As described in chapter three, this study adopted an ethnographic, inclusive video methodology to research the experiences of the older residents in Elm View. Specifically this involved seven months of fieldwork in the home. During the first three months of fieldwork, data were collected through participant observation, with the observations recorded using pen and paper. During months four and five of fieldwork, video recordings were also made in the home and shown back to the participants. Analytic themes that were developed over the first five months of fieldwork were then explored further during the final two months of pen and paper recorded participant observation. Consent was negotiated with the residents formally and on an ongoing basis over the course of the study. The Nvivo data analysis package was used to organise and code the data both thematically and on a case by case basis. The process of analysis itself was iterative and I returned to the field notes and transcripts repeatedly in the course of developing the analytic concepts and writing up the findings.

Over the following sections the implementation of the research design is described in detail.

4.3.1 Negotiating access

The many difficulties inherent in negotiating access to carry out ethnographic research was highlighted in chapter three and this study was no different as negotiating access to carry out the fieldwork involved several sets of gatekeepers. The first gatekeeper was the manager of the home, Yvonne. I initially contacted her by telephone, explaining the study to her briefly and followed up the call by sending her information about the study, including a short report of the findings of the pilot study that had been published in a newsletter for care staff (see appendix D) and a copy of a paper presented at a conference discussing the issues involved in video recording people with dementia (see appendix B). When I went to visit the home in person she had read these papers, was enthusiastic about the study, and granted me access (subject to social work approval) after my first visit to the home.

Having negotiated access with the manager of the home, I needed to negotiate access and ethical approval from the social work department (ethical approval had already been obtained from the Department of Psychology Ethics Committee at the University of Stirling). Access had already been negotiated with the same committee for the pilot study I had carried out with Gill Hubbard in the day centre. In this first instance the social work department were concerned as to the potential intrusiveness of the camera, how consent would be obtained for the participants, how anonymity might be ensured and how much staff time would be required. They also considered how useful the

research might be and requested that the research findings from the pilot be disseminated to them, including feedback on the success of the consent protocol and other arising ethical issues they should consider when reviewing future research proposals. Having received this feedback from us the previous year, the committee readily gave me approval to carry out the main data collection phase of the study in Elm View.

After access had been negotiated with the service manager and social work department, a meeting was held with the staff in the service to explain the study and find out if they were willing for it to go ahead in their service. Although it would have been hard for the staff to reject the project altogether, given that they knew it had the support of their manager, this meeting did enable them to highlight concerns they had about the project. In particular, the staff were keen to know what would happen with the video tapes after the study and who would get to see them. They also wanted to know if the project would interfere with their work in any way. Finally several of the staff said that their performance on camera may not reflect the way they normally worked and worried that they would be unable to relax whilst the camera was on. These concerns were similar to those raised by the staff in the pilot study and I was able to reassure them that the research was not about judging their practice in any way, but was examining everyday life and communication in the home. The manager was also useful in reassuring them in this regard.

It is notable that, at this stage, the service users themselves had no say in whether the project was allowed to go ahead in the home. Instead they were given the option to consent or otherwise to take part in the study, once the approval of the other parties had been given. In this way, the negotiation of access process denied them the chance to say whether they wanted the research project in their service and so actively disempowered them. This situation arose as the researcher could not have access to the attendees to ask them if they were willing for the research to go ahead, until access had been agreed with the other gatekeepers.

Having negotiated access with the gatekeepers, consent was negotiated with the residents both formally and on an ongoing basis. Residents were explained the study formally, given an information sheet and an opportunity to sign a consent form. However, more importantly their consent was renegotiated in a less formal and more fluid way during every fieldwork visit. Thus the process of gaining ongoing consent was completely interwoven into the data collection process and is described in the account of the methods used to gather the data. First, however, the formal process used to negotiate consent is described.

4.3.2 Formal negotiation of consent

The first month of field work in April 2001, was primarily concerned with seeking the consent of the residents for the study. In this time I visited the home on a number of occasions chatting to the residents alone and in small groups explaining about myself and the study. Posters were put up round the home

with my picture on, explaining who I was, what I was doing and providing contact details should anyone have any queries. After I had visited the home on three occasions getting a feel for the home and getting to know the residents I spent three visits approaching the residents more formally on a one to one basis.

During these meetings, I read through the information sheets with the residents and asked if they would be willing to be part of the study (see Appendix E for the information sheets and consent form). Specifically residents were asked to consider whether or not they would be happy for me to spend time in the home observing them; write notes about what I had observed for my study; and video record them. At this point I showed them the note book and video camera I would be using in an effort to make the process more concrete. Residents were given the opportunity to consent to parts of the study (e.g. being observed and having notes written about them) without consenting to others (e.g. being video recorded). It was emphasised at all times that I would ask the residents for consent every visit and in particular before I ever video recorded them. Residents whom I felt had clearly understood what was being asked of them were given the opportunity to sign a consent form. Residents whom I felt had not clearly understood the study were only given an information leaflet. The decision on whether or not to give the residents the opportunity to sign a consent form was informed by the views of the manager but ultimately was based on my intuition.

Residents responded to the formal consent processes in different ways. Some residents clearly understood what research was and were well able to express whether or not they wanted to take part. Indeed two of the residents had recently been involved in other research and told me about their experiences in these projects. Most of the other residents were able to understand the research process I had outlined and what their involvement would entail. However, I felt that they had not fully understood the overall aims and purpose of the research. I did not ask these residents to sign a consent form, as I felt it was both meaningless and inappropriate to ask someone to sign something that I did not think they had fully understood, however I did give these residents the information sheet. Some residents were not interested in information provided and one even said she did not want to keep a copy, however a couple of residents took an active interest in the research and told me later that they had talked the study over with their relatives. Two residents indicated that they did not want to talk to me when I initially approached them with the consent form and therefore I took this to be a refusal of consent, however all other residents agreed to be part of the study.

For the pen and paper participant observations it was decided that verbal consent from the residents was sufficient, in particular as this was going to be renegotiated over the course of the study. However the more sensitive nature of the video recording led me to seek written informed consent for all residents whose image I was to record on camera. This was unproblematic for the residents who had understood the study well and signed the consent form.

Proxy consent, however, was sought for the residents I felt were not clear what they were consenting to, or whom I felt were likely to forget the recording once it had been taken. Therefore information sheets and consent forms were sent to the next of kin detailing that the older resident had agreed verbally to be part of the study but that the written consent of the proxy was needed to enable me to go ahead and include them.

Having obtained verbal consent from the residents in this one to one setting and written consent from some of the residents and the proxies, I embarked on the participant observation phase of data collection in the home.

4.3.3 Participant observation

Most of the data in the home were gathered through participant observation. Adopting a participant as observer role, I visited the home two to three times a week for about two hours each visit. In this time I employed a number of different strategies to gain an understanding of the lives of the residents and to observe their communication. Much of the time was spent chatting to the residents and joining in the activities of the home, such as knitting in the craft room or helping with the bowls matches. Sometimes I chatted to the residents in groups, but at other times on a one to one basis. During these observations I rarely took notes, and instead found a quiet corner to write notes after the observation and wrote up detailed field notes immediately after leaving the field. During these observations I reminded the residents that I was there as a researcher and asked if they were happy for me to observe what was going on.

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Carrying my notebook, even if I did not have time to write much in it, helped to remind the residents that what I was observing would be recorded.

Engaging with the residents in this way encouraged them to talk to me about themselves, their families and their experiences in the home. During these interactions I asked residents to interpret what was going on around them and probed for their views on communication, life in the home, the other residents and dementia. At other times, however, I was a less active participant and instead sat quietly observing and writing notes about the events and conversations going on around me. Again before settling myself down, I asked the residents around for their permission to join them and take notes. Although I did chat to the residents on these occasions, I engaged less actively in the interactions and initiated far less conversation. These periods of observation were useful in that they enabled me to take in events that unfolded very slowly around me and observe the ways in which the older residents themselves negotiated their communication and life in the home without my direct interference. These quieter and less active observation periods also gave residents and staff an opportunity to ask me about the study and my activities in the home. For example one resident when she saw me writing notes was concerned that I was 'writing anything bad about the home'. Another resident, when he saw me with my notebook, would make a point of coming over and telling me his movements that day. Again these notes were written up in detailed field notes after I left the home.

Over the course of these three months of participant observation I came to know, and be known by many of the residents, who although they did not necessarily remember my name, remembered from visit to visit that I was in the home doing research. Furthermore I had become much better at explaining the research in terms the different residents understood and at discerning when they did not want me around. Therefore I felt the time was right to introduce the video camera to the residents.

4.3.4 Video recording the interactions

By the time I came to introduce the camera to the home, the residents were familiar with me and the activity of being observed. This meant that I was able to introduce the camera to them relatively easily. The first few visits to the home with the camera were spent going round to the different residents who had consented to be recorded and showing them the camera, giving them the opportunity to record with the camera and generally orienting them to the process. Before turning on the camera the residents were shown the camera, given the opportunity to feel and hold it. The interactions recorded in these first two visits were almost exclusively focused on the camera with the residents waving to the camera, asking what could be seen through the view finder and recording each other. Through this process the residents quickly became familiar with the process of being recorded, and on my third visit to the home with the camera I was able to record less contrived interactions.

As with the participant observation sessions, I used the camera to record the communication of the residents in a number of different ways. Most commonly when I observed a group of residents sitting together chatting I would ask them for permission to record and sit with the camera in my hand recording them. On these occasions I generally joined in the conversation, however, it was interesting to note that when I held the camera and looked through the viewfinder the residents rarely engaged me in conversation. However when I held the camera and maintained eye contact with them they tended to involve me and the camera much more in the interactions. The camera was used to record one to one interactions between residents and I also recorded some interactions just between me and one resident. During all these recordings the camera was very much part of the interaction and was regularly commented on by the residents. However the camera did not dominate the interactions and the residents also chatted freely with each other just as they had when I had been observing with a notebook. Indeed I continued to carry a notebook with me on these visits, writing notes about the broader context in which the recordings were taken. These notes were written up as detailed field notes after the field work visit.

Some recordings of the residents in relatively static positions were also made with the camera on a tripod. Using the tripod had the advantage that I could sit and join in the interaction, take notes and meant that the camera demanded less of my attention. I used the tripod during several of my recordings in the craft group where there was generally lots of activity to take in but the residents

tended to remain seated. During these observations I would move the camera around the room from time to time to ensure that all residents who wanted to be were given a chance to be recorded, as well as to ensure I captured clear recordings of the residents. Moving the camera also had the advantage that it reminded the residents that they were being recorded and gave me an opportunity to renegotiate their consent. The particular implications of using a video camera for negotiating consent are explored in more detail in section 4.4

4.3.5 Reviewing the videos with the participants

Having negotiated consent with the residents to video record them, I always offered them the opportunity to watch the recording afterwards. Reviewing the recordings with the residents had two advantages; it gave me a chance to elicit their perspectives on the recordings, thereby involving them in the analysis of the data and was something that they enjoyed and were keen to do. However this process was fraught with difficulties and rarely went as planned.

Playing back the recordings to the residents was a relatively technical endeavour that could be achieved in two ways. The simplest way to show the participants the recordings was to plug the camera into the back of the television and play back the tape from the camera. This had the advantage that I could show the participants the recordings immediately, however, required access to a modern television, which was something only available in a few flats in the home. Therefore more often I had to transfer the recording onto a

VHS tape away from the setting and bring the recording in on a different day to be watched by the residents.

Experiences during the pilot studies had highlighted the importance of only showing the recording to the participants who were part of the interaction (see Appendix A for a full discussion), however this was something that was difficult to achieve in Elm View. The television sets were in the communal lounges of the home and as a result anyone could walk in on the playback session at any time. Furthermore finding an appropriate space and gathering together the residents who had been recorded on a previous day to watch the recordings was a time consuming process and one that generally became noticed by other residents and staff in the home who were keen to find out what was going on. To deter others from entering the lounge where the video was being played I would shut the door, but also had to keep my hand on the controls so I could turn the recording off when others tried to watch. Preventing others from watching the recording was easier when I was able to plug the camera into the back of the television as this could be achieved with little fuss, however I still had to be vigilant ready to turn the camera off when others came in.

Experiences showing the recordings to the participants re-emphasised the need to ensure that only people who had been present at the time of the recording were able to watch the videos. Playing the recordings to the participants was a very uncomfortable process. Memory problems and confusion that were scarcely noticeable at the time of recording were much more obvious on the

recording. The camera caught all of the residents' snide remarks about each other, including about residents who were present during the recording. The camera also captured the staff members teasing the residents or communicating with them in ways that could be construed as inappropriate. The potential of the recordings to compromise the staff and residents in them was constantly reinforced as residents and staff members tried to come and watch, including residents whose behaviours had been discussed at length on the recordings.

Despite all these issues the residents very much enjoyed watching the recordings, and spent most of the time pointing at each others clothes and hair, telling each other they looked nice or teasing them for being the 'star of the show'. However one resident got very upset watching a recording of her talking about her auntie as she remembered that she had died. With the constant interruptions and upset it was hard to elicit the perspectives of the residents on the interactions captured on the recordings. They readily commented on the recording generally, and in particular felt the recordings in the craft room captured the atmosphere well. However some of the residents were unable to remember being recorded and it was hard to get past this and get them to talk about what had actually happened in the interactions and why. Given the sensitive nature of much that was recorded maybe this was for the best. Playing a recording, taken in the craft room, to the activities coordinator who had been present was however, much more useful. She offered interpretations of why different residents had behaved in certain ways during the recording and gave

me background information about the residents and other instances when they had behaved in similar ways. Furthermore the recording prompted her to reflect on her own practice in the interaction, in this case noticing when she was out-pacing the residents.

Encouraging the residents to review the recordings and offer their interpretations of the communication recorded had not worked has well as hoped in terms of including them in the research analysis. However this process was vital in helping them understand the research and facilitating their engagement in the project as a whole. Being recorded and reviewing the interactions also provided the residents who chose to take part with a diversion and genuinely seemed to be an enjoyable activity. So much so that one of the residents who had initially refused to take part in the study during the formal consent procedure actively approached me and asked to be recorded later. In this instance I did record her, but wiped over the tape immediately afterwards and did not use it as data.

4.3.6 Transcription and analysis

During the course of the fieldwork, preliminary transcriptions were made of the video recordings and the field notes and transcripts were analysed for emerging themes. However, most of the analysis and more detailed transcriptions were made after the fieldwork was finished.

The video recordings were transcribed, including four layers of information. These were: the field notes for the day as a whole; the verbal and non-verbal behaviours of the residents; interpretations of the participants of the interactions and my own interpretations. The transcripts were embedded in the field notes taken immediately after the visit, providing an overall context for the recording. Verbal and non verbal aspects of the observed interactions were then transcribed. However it is important to note that this process in itself involved a lot of analysis. In total, just under eight hours of recordings were made and to transcribe every piece of information available in these recordings was beyond the scope of the thesis. Therefore a decision was made to transcribe interactions in more detail on the basis of interest and the themes arising from the data. This meant that I returned to the tapes several times over the course of the analysis transcribing more information where it became necessary.

Having transcribed the verbal and non verbal action in the interactions, I then included notes on the participants' interpretations of the specific behaviours and interactions transcribed before including my own interpretations. The field notes and transcriptions were then organised using the NVivo qualitative analysis software programme into one project. Documents and the text within them were colour coded to making it clear what kinds of information they were referring to. Memos and comment were added to the field notes and transcripts over the course of the analysis using 'data bites'. The transcriptions and field notes were then coded allowing for themes to emerge from the data.

The actual analysis of the data involved an iterative process, moving back and forth between the raw data and developing codes as my ideas developed. The data were analysed first to explore the impact of the methods used on the experiences of the research participants and to reflect on my success at involving them in the research process. The data were then coded using free nodes to allow themes to emerge from the data. This wave of coding, in particular, highlighted the diverse meanings the residents made of their experiences of being in Elm View and the importance of preserving self-identity. The data were then coded to explore the ways in which the residents communicated and to examine the impact of different aspects of the setting on this.

These three waves of coding led to the development of a very complicated picture of the communication of the older residents in the home. The analysis revealed that the residents with dementia were able communicators and were able to assert their agency through their interactions; however it was also clear that in certain circumstances the residents were silenced, and unable to communicate. However it was impossible to discern a relationship between the communication of the residents and aspects of the home. Furthermore, analysis of the data on a case by case basis revealed that the different residents made sense of and responded to different aspects of the setting in very different ways. Therefore, at this point I returned to the raw data, explored in more detail the theoretical literature around communication outlined in chapter three. Over the course of the following months I moved back and forth

between the field notes, coded data and literature and slowly pieced together a set of analytical concepts and framework for understanding the communication of the older residents. These concepts and framework, presented in chapter five were constantly refined and redefined as I used them to create the account of the older residents communication presented in this thesis.

The account of the methods presented in this chapter has emphasised the developmental nature of the data collection and analysis process, with the methods, research questions and analytical tools changing countless times over the course of the study. It is impossible to deny the role of the researcher, research participants, or video camera in the construction of this data, or indeed in the construction of the research product. Therefore in the following section reflections on the ways in which the use of the video camera shaped the meanings the participants made of the research and the research data itself are presented.

4.4   *Reflections on the use of video in research*

As Lomax and Casey (1997) highlighted, using video provides a record of the research process that can be analysed and reflected on to examine how the use of video influenced the data gathered. In this section, findings and reflections on the use of video in the research are presented. The quality of the data gathered using video is discussed first. Then the opportunities and limitations provided by using video for encouraging participant engagement and

involvement in the research are discussed. Finally the ethical implications of using video are discussed in detail.[2]

4.4.1 Data Quality

This study employed both pen and paper and video recorded participant observation to research the experiences of older residents with and without dementia in the context of an ethnographic and inclusive methodology. This approach proved highly successful in accessing the experiences and perspectives of the residents regardless of their cognitive abilities, and highlighted the agency of the residents in the home. Pen and paper participant observation proved a useful method to gather data, allowing for many interactions in the home to be detailed along with notes about the wider context. This approach did not allow for the inclusion of more subtle aspects of interaction, in particular non-verbal behaviours, as I was unable to write fast enough to record this detail. Interactions in which I was involved proved particularly difficult to record and were generally written up from memory later.

The introduction of the video camera enabled not only the verbal aspects of behaviour to be transcribed accurately, but also non-verbal aspects of the interaction. The following example from a recording in the home at supper time

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[2]Parts of the account presented in this section have been published elsewhere (Cook, 2002; Cook, 2003). The articles, which offer a fuller discussion of the issues raised, are reproduced in appendices A and F.

shows a female resident with advanced dementia both using and interpreting

verbal and non verbal behaviours in her attempt to resist being moved to the

dining table.

> Male carer approaches the female resident, who is sitting in her
> chair, leans over and takes her hand ready to help her out of the
> chair.
>
> Carer: Your tea's ready!
>
> Resident: (looks up) Is it?
>
> C: (still holding her hand) We have some food here, some scrambled
> eggs and you'll get a cup of tea with it.
>
> R: Just a cup of tea, tea, tea
>
> C: (takes her other hand ready to pull her up) Come on trouble!
>
> R: (sits back and resists, trying to cross her arms) I am trouble,
> come over
>
> C: (still holding her hands) Aye
>
> R: (looks away from the carer) I'm stay, com, comfortable

The permanent nature of the video record meant that recordings could be

played back over and over again allowing the detection of the smallest details in

the interaction. Furthermore, replaying the interactions allowed them to be

reanalysed in light of my developing research ideas. In this way the experiences

of the participants guided the framing of the research and I was not bound to

the interpretations and recordings made at the time of the observation.

Furthermore, the use of video enabled the communication of the older residents

with dementia to be captured in context. It is important to note, however that this context was very particular. The recording of the observation above included not only the words of actions of the resident and carer, but also detailed information about the setting, including the noise of other residents, the radio, and the rattle of the meal trolley. However the interaction of the older resident was also contextualised by aspects of the setting available to the researcher, and not the camera, such as the other residents not in the field of view of the camera and the smell of the approaching food.

4.4.2 Participant engagement

The use of video enabled the involvement of the older residents with dementia in the research process by facilitating their understanding of, and engagement in the research. Many residents found to it hard to comprehend that my spending time in the setting, chatting and taking notes constituted research. Introduction of the video camera, however, immediately crystallised the research process, creating an activity that they could understand. Although the experience of being recorded was novel for the residents, they were all very familiar with video as a medium and the camera provided an immediate reminder that they were being filmed and that these films would be watched. Residents responded to this in very stereotypical ways as the following clip shows.

Beatrice looks up and sees the camera with me behind it and smiles. then Jean looks up

> Jean: Are you taking our picture?
>
> Researcher: I am
>
> Beatrice: Will we smile?
>
> Jean: Take a shot of my scarf
>
> (Beatrice laughs)

Both residents in this clip responded to the camera as something to show off to, with Beatrice later joking that I should send the clip to Hollywood to see if they would 'give us a rise'.

The novelty of the video camera and the activity of being recorded challenged residents to engage with the research and sparked interest in a way my presence as a participant observer never did. The following clip highlights this and features a conversation recorded whilst I was out of the room by a female resident, Maria, who is discussing the experience of being recorded with a fellow resident.

> 'You see it's very strange I don't myself understand. You understand about this girl, she wants to put me in the machine. You understand? If I can understand, it will be the first time I have, we will see if I like or not, it depends. If I understand I will like very much but if I don't understand why, I will be here.'

The clip clearly demonstrates the difficulties many of the residents with dementia faced trying to understand the research. In the case of Maria,

however, the special nature of being 'put in the machine' made it worth the struggle. Thus being video recorded was a formalising and validating experience for many of the participants and residents used the camera and the act of being recorded in their presentation of self. On one occasion two residents who were romantically involved asked me to record just the two of them together, which meant I had to ask another resident to move, thereby both formalising their relationship and highlighting the importance of their relationship to them.

4.4.3 Participant involvement

The increased understanding and awareness of the research fostered by the use of the video camera helped in the negotiation of ongoing consent with the residents. Not only was the camera meaningful to the residents, but it also provided a physical prompt, reminding them they were part of the research. This enabled more meaningful ongoing consent to be negotiated, residents changed their minds from day to day and even during recordings as to their willingness to be involved, as the following clip shows.

Two residents, Elsie and Geraldine had been chatting together for some time when I asked if I could record them. They both agreed and I had been standing directly in front of them recording for five minutes before Elsie remarked to Geraldine...

Elsie: this girls standing here with that stupid..., will she no sit down? There's a seat there.

Researcher: I can't see you if I'm sat down, Elsie

Geraldine: she can't see if she sits down, she wants to take a

photograph of you.

Elsie puts her head down and shakes it

G: (looks at Elsie) no?

R: would you rather I stopped?

G: I think so.

A: OK (and I turn off the camera)

Although use of the video camera encouraged residents to engage in the research and made the research process more meaningful, the camera did not overcome the difficulties the residents had understanding the research aims. Analysis of the responses of the residents to the video revealed that they reached many different understandings of the research, not all of them coinciding with mine. A common misinterpretation of the research was that it was about the life stories of the residents, as the following clip shows.

Whilst recording three residents chatting in the Foyer, one of them,

Jean, calls out to Ella who is passing...

Jean: where you going?

Ella: I dinae ken (laughs) I'm walking but I didnae ken where I'm

going

J: tell this young lady the story of your life

E: the story of my life (looks questioningly at Jean) I've nae life, I've

nae life, I've been working too hard!

(Ella laughs bitterly and sits down. Jean turns to me and says)

J: ask Ella a question, like where she used to live.

Researcher: so where did you used to live Ella?

This clip shows Jean clearly involved in the research, yet operating with a very different conception of the project to my own. In one sense this misinterpretation has few consequences for the study; Jean's question generated interesting data. However this recording is evidence that Jean's consent to participate in the study is misinformed, which is problematic for any research, not least that which seeks to avoid disempowering the research participants. The response of a resident with more advanced dementia, in the following clip highlights this problem more starkly still.

I approach three residents who are sitting in the foyer and ask if they are willing to be video recorded, explaining that it is for my study at the university on the communication of older people. They all agree, however the first thing recorded when the camera is turned on is...

Nan: What's it for, the paper?

Jean: It's not for the paper, (to the researcher, joking) the News of the World is that where you're from?

Researcher: It's for my project

N: What?

R: My project

J: (to the researcher) She doesn't ken what a project is..

R: My university studies

N: I didn't know what you said (looking at me)

R: Right (pause) you can watch the video when it's done.

Therefore Nan, although clearly engaged with the research, cannot be said to have given informed consent for participation, raising a question as to whether I should include this data in the research.

To involve the residents in the data collection and analysis of the findings, residents were encouraged to use the camera themselves and were shown the findings and asked to comment on them. Neither method proved very successful. Many of the participants in the study readily handled the video camera and recorded with it, however none of the residents in the home were able to see through the viewfinder. This meant that they had no control over what was filmed, rendering them unable to contribute to the data collection process in this way. The residents were, however, able to be involved in determining the data collection in different ways. The video camera provided a physical frame to the research, which residents were able to manipulate, giving them control over the data collection process. Residents commonly responded to this frame by 'voting with their feet' - moving in and out of the research as they chose. One resident in particular, however, acted as a director; calling people in and out of the frame of recording and ensuring she was seen in a good light.

Two residents are sitting in the lounge as I ask if I could record them chatting.

Jean: you can get that big handsome felle in, (then calls out to the passing man) come over here and get your picture took! (Nan turns round to look as does Jean, who then sees Ella)

J: Ella you going to get your picture taken?

Ella: Eh? (as she slowly approaches)

J: you can get a seat up here, (pointing to a chair) you can get a sea round that way, you're getting your picture taken.

E: am I?

It is important to note, however, that Jean's active role in the research had implications for Ella, who through Jean's action was unwittingly drawn into the research without giving consent to be recorded on this occasion.

These reflections on the data highlight two key issues for understanding the data gathered using the video. First, what the participants think the camera sees is as important as what is captured through the lens. Secondly the video recorded observations are not neutral records, but social and technical constructions, influenced by the camera, the researcher and the perceptions of the residents of both. Use of the camera also raised a number of ethical issues which are explored in the following section.

4.4.4 Ethical Issues related to using video in research

The research findings presented here reveal that there are a number of ethical issues to be considered when using video in research. Using video observation to record the experiences of research participants places them in a vulnerable position, as they give the researcher a resource that could be used to their disadvantage. This potential for harm, intentional or inadvertent, is greater for those who are disempowered or face social exclusion, as many people with dementia, and the staff who work with them do. It was clear from this research that many of the participants had not considered the damaging ways in which the video recordings could be used and trusted the researcher to act in their best interests. Careful consideration of these issues has led to the identification of three key ways in which the researcher may wittingly or unwittingly place their participants in a compromising position or add to their exclusion and disempowerment. These are: objectifying the research participant; leaving the research participant open to judgement; and violating the right of the research participant to anonymity. These are described in detail below.

During the research process, there is a danger that the video may be used in a way that objectifies the research participants or their experiences, and emphasises their 'otherness', thereby adding to their exclusion and disadvantage (Fine, 1994). Previous research using video to investigate aspects of dementia has been guilty of doing this, by using the camera to examine the experiences of the 'subjects' as if they were in a goldfish bowl. Smith (1995), for example, video recorded people with dementia and what he

termed 'normal controls' watching video clips and analysed the recordings using a coding schedule to see if people with dementia (viewed as a homogenous, diagnostic group) responded to images of people expressing emotion with facial expression. In this way the research objectified the individuals involved as members of a diagnostic category with a specific communicative dysfunction. Fine (1994) stresses how this type of research objectifies the participants and serves to add to the exclusion that disadvantaged groups face. Instead, she calls for researchers to include the voices of the participants in research and emphasise the heterogeneity of their experiences. Therefore it is essential if the research is to facilitate inclusion, that the perspectives of the participants are ascertained wherever possible.

This research sought to include the perspectives of the participants by showing them the videos and asking them to offer interpretations of the interactions recorded. It is important, however, that the video recordings of the participants with and without dementia are not shown to families or other people in that setting, unless they too were involved in the interaction. Participants with dementia in this study were observed to use humour and gestures in ways that might appear to be childlike or crude when taken out of context. Showing these recordings to others involved in the setting, but not the particular interaction, leaves the residents open to judgement.

Given the potentially stigmatising nature of a diagnosis of dementia, it is equally important that the images of people with dementia are not shown to people in

the wider community, unless permission is expressly given from the person with dementia himself or herself. When disseminating research on dementia, it is very tempting to use the powerful visual images captured on camera to enhance conference presentations or training videos, however this both identifies who the research participants are, and that they have dementia. This means that it is no longer within the control of the person with dementia who does and does not know their diagnosis. Furthermore that person is inherently linked to any interpretation that the researcher puts on the data, regardless of whether they agree with it or not. Putting images of people with dementia on the Internet is potentially even more damaging. Not only does it increase the numbers of people who may identify that individual as having dementia but unless extreme care is taken, others may download the image and use it in ways neither the researcher nor the participant can control.

To address this specific issue in the dissemination of the findings from this study, funding was sought with colleagues at the University of Stirling to hire actors to represent research findings visually without compromising the anonymity of the research participants. Data from this study and an ESRC funded study looking at the quality of life of older people in institutional care on the sexual expression of older residents was dramatised and recorded in collaboration with colleagues from the Department of Film and Media at the University of Stirling and from the Royal Academy of Music and Drama. These short excerpts of film were then integrated with academic text by a team of multimedia designers from the University of Dundee and published on a CD-

ROM (Hubbard et al, 2003, Appendix G). This method of dissemination enabled the visual research findings to be disseminated in a very powerful and meaningful way. It was however a costly and time consuming process and raises a number of issues regarding the representation of research data. These are discussed in detail in the CD-ROM.

4.5 Conclusion

The development of the methods and methodology in this study has been particularly important in shaping the overall thesis. The study adopted a flexible and reflexive approach to understanding the communication of the older participants with dementia from the outset. This was essential in the development of the study as it enabled me to shift both the methods and the research questions in response to experiences in the field, in particular during the pilot study. Thus, over the course of the first year of the research, the study changed substantially in focus, from looking at the ways in which carers facilitated the communication of older people with dementia to focusing exclusively on the experiences of older people with dementia themselves.

The main body of data in this study was collected in one care home, which was recognised for providing good care and where there was a lot of easily observable communication. Participant observation was used to gather the data, which were recorded using both pen and paper and a video camera. The use of these methods within the context of an ethnographic, inclusive, exploratory methodology enabled detailed information about the communication

of the residents, their lives in the home and the meanings they made, to be gathered. In particular, the use of video enabled detailed information about the visual as well as verbal aspects of the experiences of the older residents to be captured and included in the analysis.

Central to the methods was the involvement of the older residents in the research. This was done through gaining their consent for participation using formal and informal procedures; eliciting their perspectives and interpretations on both life in the home and the data gathered; and in involving them in decisions regarding data collection. The video camera proved particularly useful in supporting the involvement of the participants in the research. The familiar nature of the camera meant that the residents easily understood that they were being recorded. The camera provoked the interest of the residents, encouraging them to engage with the research process. Furthermore the camera provided a concrete frame for the research making it easier for the residents to know when they were 'being researched' and to opt in and out of the research as they chose. However, the use of video in the study raised number of ethical issues to be addressed. In particular the videos had to be guarded carefully, and were only shown to the research team and the people who had been recorded to ensure the anonymity of the participants and to avoid their potential disparagement.

The exploratory nature of the research demanded that analysis was iterative and the framework for analysing the data was developed over time. The data

was coded using Nvivo in multiple waves as the themes and framework developed. The framework developed through this process is presented in the following chapter. In chapters six and seven the key findings relating to the influence of living with dementia in a residential care home on the communication of the older residents are presented.

Chapter 5

Framework for Understanding Communication

5.0 Overview

This chapter outlines the framework used to understand the communication of the older residents with dementia in Elm View in this study and introduces the residents on whose communication the findings are based. As highlighted in chapters three and four, the exploratory nature of the research demanded that the framework and concepts used to understand the data were developed over the course of the analysis. Recourse to the theoretical literature presented in chapter three was useful in that it provided an overarching frame through which to understand social life generally and aspects of communication specifically. In particular this literature was useful in highlighting the ways in which communication is interwoven in social life, and in sensitising me to the interactions the older residents were having with structures, ideas and themselves as well as others in the setting. This literature did not provide a coherent set of concepts or framework to address the research aim of exploring how living with dementia in a residential care home influences the communication of older people. Therefore a key task of the analysis was to develop such a framework. However, the work of Charon (1994) did offer a number of concepts useful in starting to understand the communication of the older residents.

In the conceptualisation of social interaction outlined by Charon (1994) and described in chapter three, communication is seen as being part of a cycle, interwoven into the stream of action of the older resident. The smallest unit of analysis in this cycle is the communicative act. A communicative act might be a gesture, question, or statement and is the response of a person to a meaning or set of meanings they made from their situation. However, a communicative act is also the stimulus for the processes of meaning making and response for another person, as the following example shows.

> Three female residents with dementia are sitting in the foyer of the
> home. In the course of the conversation Jean turns to Ella and says
> J: When are you going?
> E: I'm going right on!
> J: On where?
> E: I'm not telling you where I'm going, it's a secret.

Therefore to understand how something influences the communication of an older resident the researcher must interpret both the meanings the resident made of that influence and their response to the meanings made. This excerpt of conversation, however, highlights how difficult it is to reach an interpretation of the communication of older people with dementia. In this interaction Ella might be resisting telling Jean where she is going because she is going to buy her a present, or because she herself does not know where she is going, but does not want the others to realise. Looking at the interaction within the wider

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stream of action however, makes it easier to reach a more plausible interpretation.

Ella, Nan and Jean, all of whom have dementia, are sitting together in the Foyer of Elm View. They had been having a somewhat confrontational and tangled conversation about their past lives in which Nan and Jean have been asking Ella about where she was from and Jean had been asking personal questions about money that Ella was both unable and unwilling to answer. This conversation has left Ella feeling upset. After a short pause Ella turns to Nan and the following conversation ensues:

E: You're going home aren't you?

N: Pardon

E: You're going home? (Emphatically)

N: When? (Confused)

E: Well, when its time for going!

At this point Jean interjects in a challenging way

J: When are you going? (Nan sits back and lets Jean take over the conversation)

E: I'm going right on (sounding annoyed)

J: On where?

E: I'm not telling you where I'm going, it's a secret (defiantly)

J: I ken where you're going, you'll be sitting here tonight on all.

E: No I wont!

J: Wan'nae bet (Taunting Ella)

E: No

J: I'll see you tonight and I'll say 'Hello Ella'

E: Aye, you'll see Ella, bright and bride! (Ella gets up and turns to Nan pointedly and says) See you tomorrow (and starts to walk off)

N: yes alright (looking implacable)

J: Bye

N: Good bye, certainly

E: I want to get away over to see my mother (and turns and leaves finally)

J: (addressing the camera / researcher) You'll be lucky! (Turns to watch her go)

N: It'll have been her age that's done it to her. (Nan and Jean look at each other meaningfully)

J: I bet she's younger than you!

This fuller context suggests a very different interpretation of the interaction. The meanings Ella makes in the previous difficult conversation prompts her to try to leave the situation and go 'home', and so turns to Nan for support with this, asking if she too is going home. Nan, who at that time is aware that this is her home, delays having to respond directly to Ella's confusion by pretending she has not heard and then disengages from the conversation until Ella has left. The hesitancy of Nan, however, provides Jean with an opportunity to taunt Ella, thereby demonstrating to herself and the camera / researcher that she is not confused like Ella. In turn, Ella acts in ways to resist both the efforts of Jean to taunt her and the reality that she cannot leave the home.

This interpretation still begs more questions than it provides answers. Although it is clear that Ella does not think of Elm View as her home, it is impossible from this snapshot to understand why she responds to the home in this way. Similarly it is not clear why Nan and Jean respond to Ella's expression of her dislocation in such different ways. To gain this level of insight it is vital to understand the meanings the residents made of the communicative behaviours and stimuli they encountered in the course of their interactions and to understand why they responded to these meanings in the ways that they do.

In this chapter a framework for understanding how the meanings the older residents made of living with dementia in a residential care home influenced their communication of the older residents is presented. Specifically the framework breaks down the communication process into constituent parts and identifies key factors influencing the process. In this way, an understanding of the ways in which the stimuli that the residents encounter in their interactions in the world influence their communication is developed. It is important at this point to note, however, that the framework outlined in this chapter focuses on understanding the communication of the older residents symbolically. That is, in relation to the meanings they made in their interactions. Analysis of the data revealed that the communication of the older residents was also influenced materially by their experiences of living with dementia in Elm View. In chapters six and seven analysis is presented that examines the ways in which the communication of the older residents was influenced both symbolically and

materially. However first the framework for understanding the communication of the older residents symbolically is developed.

In section 5.1 the underpinnings of the framework are outlined. The meaning making and responding processes are then considered in detail in sections 5.2 and 5.3 respectively and key concepts guiding understanding are explained. In section 5.4 the residents, whose communication forms the basis of this study, are introduced. In section 5.5 the approach taken to understand the ways in which living with dementia in a residential care home influenced the communication of the older residents both symbolically and materially is outlined.

5.1 Underpinnings of the framework

The framework for understanding communication used in this study is grounded broadly on the symbolic interactionist perspective in particular as outlined by Blumer (1969). Symbolic interactionism is based on the assumption that social actors make meaning of themselves and the world through interactions with others, ideas, objects, structures and space. Decisions regarding how to respond to the things a social actor encounters in the world are based on the meanings they make in interaction with that thing, as opposed to how it is generally perceived. This means that any understanding of communication must be grounded in an understanding of the individual communicating in relation to their context. Furthermore the approach highlights the dynamic nature of the meanings made, with the meanings an individual makes in one

situation influenced by the meanings they have made in previous encounters in the world. In this way the approach adopted in this study is different to previous research on the communication of older people with dementia, which has tended to focus on the communicative behaviours themselves and to ignore both the individual communicating and their context.

Adopting such an understanding of communication demands that the framework used to analyse the findings must be both flexible enough to embrace the circular, interpretative and dynamic nature of interaction, and firm enough to reach an understanding of the behaviours, gestures and vocalisations under investigation. Over the course of this chapter a framework is presented for understanding the responses of the residents to the meanings they made of stimuli encountered in their interactions in the world. This framework conceptualises communication as consisting of two key processes, meaning making and responding. Meaning making refers to the process by which the older resident makes meaning of things they encounter in the world around them. Responding refers to the process they undergo when deciding how to act following meaning making. These two processes can be broken down further into five phases of interaction. These are: encountering; interpreting; evaluating; decision making, and responding. Interactions, triggered by an encounter with a stimulus, are made up of many cycles of these phases linked together, with the act of one person being the stimulus another person encounters. Figure 5.1 illustrates how the processes and phases fit together and presents a description of each of the phases.

Fig 5.1 Processes and phases of an interaction

Process	Phase	Description
Meaning making	1 Encountering	Resident encounters a stimulus in the stream of action
	2 Interpreting	Resident interprets the meaning of the stimulus
Responding	3 Evaluating	Resident evaluates the impact of the meanings they made on what they want to achieve from the interaction
	4 Decision making	Resident makes a decision about whether to accept or reject the meaning in light of its impact
	5 Acting	Resident responds through generation of a communicative act

Over the following sections the two processes are examined in detail. A number of concepts are outlined to enable the factors influencing the processes as they occur in each phase of an interaction to be identified and understood. In section 5.2 the meaning making process is explored in detail. Section 5.3 examines the process of responding.

5.2 Meaning making

Central to the approach to understanding communication used in this study is the recognition of the importance of meaning making, and that communication

is based on the meanings a person makes in their stream of action. Therefore the first and most important task in seeking to understand the communication of older people with dementia in residential care is to develop an understanding of their meaning making process. The excerpt of data presented in section 5.0 highlighted what a challenging endeavour this is. Analysis of the data, however, revealed three key factors informing the meanings the older residents made when they encountered any given stimulus. These are the context with which they are interacting, the perspectives the residents bring to make meaning, and the stream of action in which they encounter the stimulus. These three factors are summarised in figure 5.2 over the page.

Fig 5.2 Description of factors influencing the meaning making process

Factors	Context	Perspectives	Stream of action
Definition	The meanings the social actor makes of the social and physical space in which an interaction occurs	What the person brings of themselves to make meaning in an interaction	The flow of action surrounding any given communicative act
Key features	Multifaceted, dynamic, constantly shifting, different facets assume different importance at different times	Influenced by the life history, sense of self, significant others, goals, reference groups and values of the older resident	Includes verbal and non verbal aspects of communication, influenced by others and the context

This brief summary highlights the dynamic and nebulous nature of each of the three factors influencing meaning making. These factors and the means by which they can be accessed and understood are outlined in detail over the following sections.

5.2.1 Context

Central to the understanding of communication adopted in this study is the recognition that communication does not happen in a vacuum, but occurs in context. This context is multifaceted including the people around, the social situation and space in which the interaction is occurring and the social conventions and discourses operating in the interaction. This multifaceted context influences the communication of the residents in two ways as they interact both with facets of their context and within that context. Furthermore, the context varies from interaction to interaction, as do the facets of context that have the most bearing on and therefore that are the most salient to interpreting any given interaction.

Gaining an understanding of context is vital to interpreting communication and is a challenging enterprise in itself. Some aspects of context are fairly concrete and easy to observe, such as the physical environment of the home, however the researcher must access other aspects of context such as societal discourses around ageing in a different way. It is also important to note that it is not the context as constructed by the researcher that influences the communication of the older residents, but context as made meaningful by the

older residents themselves. Therefore it is never possible to know what the context is for any given interaction; it can only be interpreted. Analysis of the findings in this study revealed two key facets of context that were particularly important to understanding how living with dementia in a residential care home influenced the communication of the older residents. These are the societal context and the institutional context.

The societal context refers to the structures and processes outlined in chapter two, in which the residents live and influence the meanings they make of themselves and the world around. These structures and processes include political systems, welfare entitlements, class, the media, and discourses around ageing, dementia, and institutionalisation. When the residents acted to make sense of themselves and their situation as older people with dementia living in residential care, they interacted with a set of understandings about these facets of their experience constructed by society. Thus interactions with and within this context are not with material objects or people per se, but with the construction of the residents of a 'generalised other'.

The second context, the institutional context, refers to the structures, spaces, practices and people within a clearly defined social and physical space, the residential home Elm View. Residents interacted both with and within this facet of their context. However, the interactions of the residents with this context were qualitatively different from the interactions with the societal context as they

occurred between the residents and the institution as it was experienced materially by them.

The excerpt of data presented in section 5.0 sheds light on some of the ways in which these facets of context influenced the processes of meaning making of the older residents. The response of Jean to Ella's efforts to leave 'you'll be sitting here tonight an all' is clearly informed by the meanings she has made of the institutional context as somewhere they all spend the night. Furthermore Nan's comment 'it'll have been her age that's done it to her' reflects the meanings she has made in the societal context, that confusion is associated with old age. In these ways the societal context influenced the communication of the older residents symbolically, as they made meaning of the context.

5.2.2 Perspectives

The excerpt of interaction presented at the start of this section revealed that the residents brought different perspectives with them to the interaction that influenced the meanings they made in the interaction. Therefore to interpret the meanings a person makes in an interaction it is vital to understand the perspective they bring to make meaning. In this study, the concept of 'perspective' is used to refer broadly to the resources the older residents convene to make sense of any given meaning in the world around them. These resources include the sense of self-identity of the residents; their relationships; shared meanings developed with significant others; exposure to cultural discourses; previous experiences and life history. In this study the perspectives

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a person brings to make meaning in any given interaction are seen as being dynamically created, with different resources being drawn on in light of the stream of action the social actor finds themselves and constantly being reappraised in light of new experiences. Thus in Elm View the perspectives of the residents were shaped by family, employment, cultural discourses around ageing, dementia and institutionalisation, and new experiences encountered on moving into Elm View. Although the perspectives of the residents were dynamically created, many of the resources the residents convened to make meaning of the world remained static and thus many of their perspectives were relatively enduring. In short, the term 'perspective' is used to refer to what the residents brought with them from their life history, both recent and long past, to make meaning in an interaction.

This use of the term perspective is much broader than that elucidated by Charon (1994) who identified perspective as being just one of nine things a person brings to make sense in an interaction along with mind, self, symbols, significant others, reference groups, past experience, interests and goals. Although conceptually elegant, this division of what a person brings to an interaction into nine distinct parts proved meaningless when applied to the experiences of the residents in this study, whose senses of self identity were tied up with their past experiences, significant others etc. Instead the concept is closer to that elucidated by Prus (1996) who used it more generally to refer to the things people bring to make meaning in interactions.

It is important to note that as with the context for the interactions it was not possible to know the perspectives of the residents, they could only be interpreted following prolonged inter-subjective engagement with each person. The perspectives of the older residents in this thesis are presented in section 5.4.

5.2.3 Stream of action

In this study the term 'stream of action' refers to the flow of action surrounding any given communicative act. Thus the stream of action consists of many cycles of the five phases outlined in section 5.1 linked together. The stream of action refers to both the flow of action surrounding a person and the flow of action surrounding a given interaction, such as the one outlined in section 5.0. Just as with streams of water, individuals and their streams of action converge and diverge to make and break larger streams of action. Furthermore the path of a stream of action is influenced by the social actor, or actors, involved in it, by the context in which it occurs and by what is encountered in the stream. Therefore the stream of action although always moving forward, meanders changing direction in response to what is going on around and within it.

It is important to reiterate at this point that communicative acts occur not only in interaction with people, but may occur in interaction with any social object, including material objects such as cutlery and chairs, spaces, structures and ideas. For example, during the interaction between Jean, Nan and Ella, Jean is observed to interact both with the other residents and the video camera.

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Furthermore, the use of space by Ella in this interaction clearly shows that the communicative acts of the residents included use of space and objects as well as gestures and vocalisations. Finally, the stream of action is influenced not only by the actions of the social actor and the social object with which they are interacting in that moment, but also by events unfolding at the periphery of the action, which may influence the decisions taken during an interaction about how to respond next. This account of the stream of action highlights how the communication of the older residents is influenced symbolically, by the meanings they make of the context and action unfolding around them, and materially as the context and social actors around shape what the older residents encounter in their streams of action.

Relative to the context and perspectives of the residents, on first examination the stream of action appears fairly straightforward to access. It is experienced directly by any researcher present during the stream of action and consists of concrete behaviours that can be observed and recorded. However, gaining an understanding of the stream of action requires that the researcher observes and records a plethora of information. This includes: the verbal and non-verbal behaviours of the social actors present in the stream of action (including the researcher); other social objects with which the participants interact; and action ongoing around the stream of action. The use of video in this study has provided a key contribution to accessing much of this information. However, as the account of the analysis presented in section 4.3.6 highlighted, it was never possible to record all the information of possible relevance to understanding the

communication. Instead transcription and analysis entailed a constant process of determining which aspects of information were most pertinent to understanding the communicative act under investigation. Therefore although grounded in relatively concrete, tangible data, the record of any given stream of action is as much a construction as the accounts presented in this thesis of the context or perspectives influencing meaning making.

5.2.4 Interpreting meaning

Over the previous pages three factors for understanding the meanings the older residents made were outlined. However, as figure 5.1 highlighted, there are two phases to meaning making, and before a meaning can be interpreted it must be encountered. Residents interpreted the meanings of stimuli that they encountered in their streams of action. These stimuli were often the communicative acts of others, however residents also encountered other social objects such as ideas, structures and spaces in interactions with and within facets of their context. Furthermore residents interpreted and responded to stimuli encountered in interactions with their self as well as with others and the world around. Therefore a key challenge in interpreting meaning making is identifying the stimulus that the older resident is encountering and on which the interpretation is based, as the following excerpt from field notes illustrates.

As I walk past the door to the flat I see Elsie with her back to me scrubbing the doorframe with an incontinence pad. When I go up to

her and ask her how she is she turns and talks to me quite confusedly about how she has to clean but is 'beat'.

In this example Elsie can be observed to respond to two stimuli, my question and whatever prompted her to engage in cleaning the doorframe. This example illustrates clearly that while some stimuli are easy to identify, others are more difficult to discern. In this instance it is hard to know what prompted Elsie to respond to the door frame and incontinence pad in this way. She might have seen the doorframe was dirty and found whatever she could to clean it, or she might have found the incontinence pad, mistaken it for a cloth and then tried to find something to clean. Alternatively she may have been responding to some internal stimulus that urged her to clean.

Having established what the older resident is interacting with, the second challenge in interpreting meaning is to elucidate how the three factors outlined are influencing the meanings made of any given stimulus. As highlighted in this section, however, reaching an understanding of the meanings the older residents made demands not only that their behaviours are examined in relation to these three factors, but that the factors themselves are interpreted. This means that any account of communication developed through analysis in this way is just one of many possible constructions. Furthermore such an approach demands that the researcher engage in in-depth exploration of the context and the people interacting within it.

Examination of the excerpt of data presented in section 5.0 highlights the extent to which the three factors influencing meaning making were interdependent. The institutional and societal context in which the residents interacted influenced both the perspectives they brought to make meaning and the ways in which they acted in the stream of action. Furthermore the meanings they made of the context were influenced by their perspectives, leading the different residents to respond to the context differently. The perspectives of the residents also influenced how they acted in the stream of action. In turn, the stream of action influenced the perspectives of the residents as the meanings they made in the stream of action constantly led them to reassess their values, sense of self etc. Finally the stream of action influenced the meanings the residents made of their context as through interactions in the stream of action they came to see their context in different ways. For example Jean challenged the meaning Ella had made of the institutional context as being somewhere she could leave. This interrelation between the three factors is illustrated in figure 5.3.

Figure 5.3 Interrelations between context, perspectives and stream of action
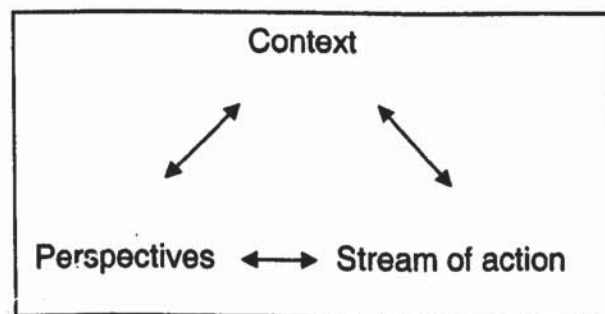
This section has outlined a framework for understanding the meanings the residents made in the course of their interactions. However understanding the meanings the older residents made in their interactions only constitutes half of the challenge of understanding their communication. To develop a more complete picture of the influence of living with dementia in a residential care setting on the communication of the older residents it is vital to examine the factors influencing the response of the older residents to these meanings. In the following section a framework for understanding the decision making process the residents undertook when responding to the meanings they made is presented.

5.3 Responding

The interaction Elsie had with the doorframe described in the previous section highlighted the importance of understanding not only the meanings the older residents made in their streams of action, but also their responses. This section outlines the key concept used to understand the response process, the 'projects' of the residents, and describes how the projects of the residents influenced communication across the three phases of interaction involved in the responding process.

Analysis of the data revealed that the responses the residents gave to the meanings they made in their streams of action were governed by the impact of those meanings on what I term their 'projects'. The term project refers to what the residents seek to achieve in an interaction and are described in detail in the

following section. In section 5.3.2 the ways in which the concept is used to understand the process of responding is described.

5.3.1 Projects

Charon's (1994) model of communication argued that social actors made a decision regarding how to respond to any given meaning made in the stream of action with reference to their 'goals' in the interaction. As described in chapter three, Goffman (1959) has done most work to elucidate this concept, arguing that the key goal of any interaction is the presentation of a desired self to those around. Analysis of the data in this study, however, revealed that the decisions the older residents made in their interactions were better understood with reference to their 'projects'. Denzin (1992) used this term to refer to what social actors do. In this study the term project is used to refer to the programmes of 'work' that the residents carried out through their interactions. Thus the projects of the residents determined what they sought to achieve in any interaction. These projects were enduring, requiring the residents to work everyday for the rest of their lives. In this way the projects of the residents were distinct from the goals of interaction referred to by Blumer (1969), Goffman (1959) and Mead (1934) which are conceptualised as being short term, defined and responded to within the specific interaction. Analysis of the data revealed three key projects that the residents in Elm View were forced by their circumstances to engage in. These were preserving self-determinacy; preserving and creating social relationships; and preserving self-identity. As with the factors influencing

meaning making, these three projects were interrelated. The relationship between the projects is shown in figure 5.4.

Fig. 5.4 The three projects of the older residents in Elm View

Self-determinacy ⟷ Social relationships

Self-identity
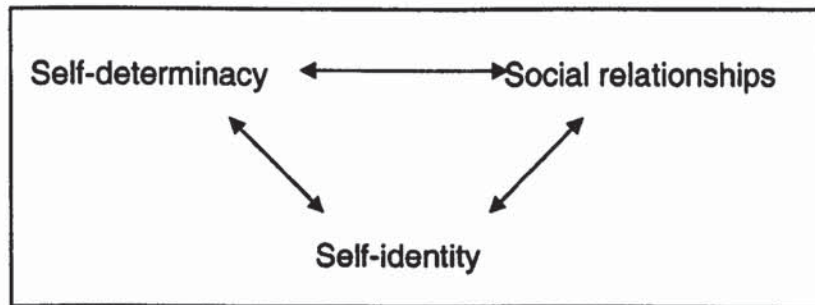
In this study, the term self-determinacy is used to refer to the abilities and opportunities the residents have to do what they choose and to continue to live out the routines, habits and rituals they developed over the course of their life times. In the interaction presented at the start of the section, Jean's comment 'you'll be sitting here tonight an all' clearly reflects the extent to which the self-determinacy of Ella was threatened in the setting. However, the behaviour of Ella in this conversation and in particular her insistence that she is going home serves to preserve her self-determinacy or at least her experience of her self-determinacy if not actually what she was able to do.

The second project the residents were forced to engage in was preserving and creating social relationships. Examination of the conversation between Jean, Nan and Ella shows that both Nan and Ella responded in ways that reflected their projects of preserving and creating social relationships. By her actions of 'getting away to see her mother', Ella acted to preserve this important social

relationship. The response of Nan in this interaction, however, suggests a wish to preserve her social relationships with both Jean and Ella. At different times in the conversation Nan takes the side of Ella and Jean, saying goodbye to Ella politely and then supporting Jean's challenge of Ella, commenting 'It'll have been her age that's done it to her.' However, preserving social relationships is clearly not a project informing the responses of Jean in this interaction as she challenges and disagrees with both Ella and Nan. This excerpt of conversation reveals something of how projects influenced communication, which was that not all projects influenced every interaction, but came into play depending on the meanings made in the stream of action.

The final and most important project is that of preserving self-identity. Examination of the excerpt of data presented in section 5.0 highlights examples of all the residents acting in ways to preserve their self-identity. Nan worked to preserve her self-identity by disengaging from the conversation to avoid making an inappropriate response. Jean challenged Ella's confusion to present herself as not confused and more able than Ella. Ella, however, preserved her self-identity by hanging onto, and continuing to act out the belief that she can both get home and see her mother. It is important to note that although all the residents shared the same three key projects, they differed in term of what these projects meant to them and how they might be fulfilled. The perspectives of the residents influenced the kinds of self-determinacy, social relationships and self-identity they sought to maintain through their interactions. For example, Ella's project of preserving social relations centred around keeping alive her

relationship with her mother, whilst preserving social relationships with both Ella and Jean was clearly important to Nan.

As illustrated in figure 5.4, the three projects are conceptualised as being in a web of interdependence. This means that when one project is threatened or supported this has a bearing on all the projects. For example, when a resident has a positive self-identity they are more likely to have self-determinacy, which in turn enables them to take opportunities to ensure they have positive social relationships too. Similarly when the self-determinacy of a resident is challenged, they are likely to be less able to maintain social relationships and experience a less positive self-identity. Examples of this inter-relationship are explored in more detail in chapter six.

5.3.2 Understanding the process of responding

The discussion in the previous section outlined the ways in which the term project can be used to understand the communication of the older residents. Specifically examining the communication of the residents in relation to their projects provides three clear drivers to explain their communicative behaviours. However, conceptualising communication in relation to the projects of the residents alone does not help understand the process of responding. As outlined in section 5.1, the process of responding is conceptualised as constituting three phases, evaluating, decision making and acting. These are described in the following paragraphs.

In the first phase of the response process, evaluating, the social actor evaluates the impact of the meaning they made of the stimulus on what they want to achieve within the stream of action. The projects of the residents represent what they want to achieve in the stream of action. Therefore when the residents evaluated the impact of the meaning made they did so in relation to their projects. Analysis of the data revealed two key ways in which meanings impacted on the projects of the residents as illustrated in figure 5.5. Some meanings that the residents made supported one or more of their projects. This means that the meaning helped preserve the self-determinacy, social relationships or self-identity of the residents. Other meanings, however, were threatening to the projects of the residents, in other words, they challenged the efforts of the residents to preserve their self-determinacy, social relationships and self-identity.

Examination of the conversation between Nan, Ella and Jean using this conceptualisation reveals that overall it was a very threatening interaction for all three residents. The residents directly challenged what each other were saying over the course of the interaction, threatening each others' projects of preserving self-identity. Furthermore, the meanings Ella made in conversation with Jean directly challenged her projects of preserving her social relationship with her mother, and her self-determinacy to get home. However, not all meanings the residents made of stimuli encountered in their streams of action impacted on the projects of the residents. Indeed, many meanings the residents made were neutral neither directly supporting nor threatening their projects.

Instead residents responded to these meanings in terms of their potential to threaten or support. The ways in which residents negotiated these neutral meanings are discussed in more detail at the end of the section.

In the fourth phase of interaction, decision making, the resident must decide how they are going to manage the meaning they made in their interaction, in light of the impact of that meaning on their project. In the framework three key choices for the residents are conceptualised: to accept, reject or ignore the meaning they made of the stimulus. The decision made in this phase is influenced again by their projects, but also by the three factors that influenced meaning making, the context, perspective of the resident and stream of action. Therefore whether or not a resident will reject a meaning depends not only on the impact on their projects, but also the situation very generally that they are in. In many situations the residents will accept meanings that support their projects and reject meanings that threaten them, as these are the strategies that, on the surface, help them maintain projects best. However the situation is not always straightforward. The literature reviewed in chapter three highlighted that some meanings are more powerful and pervasive than others are and therefore more difficult to reject, no matter how damaging they are to the projects of the residents. Over the course of the analysis presented in the following two chapters the ways in which the residents negotiated this decision making phase of their interactions are explored in detail.

Conceptualising the responding process in relation to threats and supports to the projects of the residents provides an explicit frame through which to explore how processes of social exclusion and marginalisation are reproduced and experienced by residents through their interactions in the world. The literature reviewed in chapter two highlighted the ways in which older people with dementia living in residential care are marginalised and excluded through being separated from their families and communities, denied choice and depersonalised. Thus meanings that threatened their projects served to perpetuate their experiences of social exclusion and marginalisation, whereas supportive meanings redressed these processes.

The final phase of the interaction is acting. In this study, the action a resident takes in response to the meanings made of a stimulus encountered in the stream of action is conceptualised as being influenced by whether or not the meaning was threatening or supportive to the projects of the resident and whether they decided to reject, accept or ignore the meanings. This chain of events is illustrated in figure 5.5.

Figure 5.5 The responding process
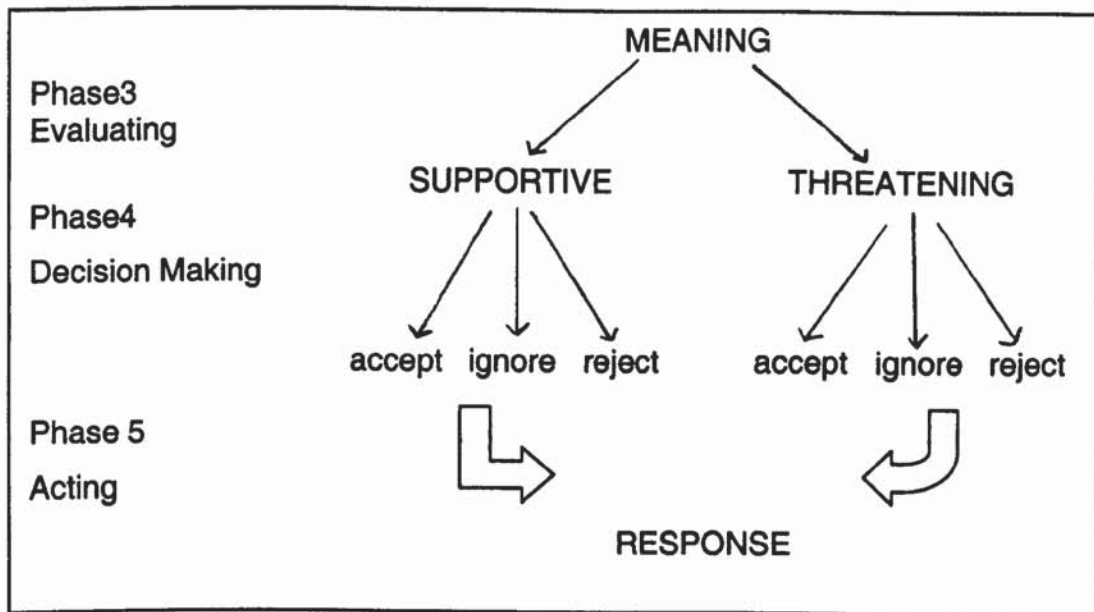
It is important to note that the framework does not enable the researcher to make a prediction about the action a resident might take in response to any given stimuli. Instead it provides a frame for understanding the decisions a resident took leading them to act in the ways that they did. However, examination of the excerpt of communication presented in section 5.0 reveals that this is a somewhat simplified description of the process of responding. As already highlighted, not all of the meanings the residents made had a direct impact on their projects. Furthermore, the three projects of the residents were interrelated and the residents had to negotiate the relative impact of meanings made on all three projects. This meant that communication could not just be the simple process of accepting, rejecting or ignoring the meanings the residents made and responding accordingly. Instead the actions of the residents were more sophisticated and innovative and reflected their effort to preserve their projects in whatever way they could. One example of this is the ways in which

the residents acted to pre-empt potentially threatening meanings. Nan's response, 'pardon', to Ella's initial question of when she was going home was a good example of this. Examining Nan's action of saying 'pardon' using the framework outlined in this chapter reveals that Nan did not interpret Ella's statement 'You're going home aren't you' literally and consider the impact of Ella's assertion that she too is going home on her projects. Instead Nan interpreted Ella's statement symbolically as a sign of her confusion and disorientation. Although this did not impact directly on her projects of preserving her self-identity as a non confused person, Nan made a very neutral response to give her time to watch the interaction unfold before she decided how to respond to the confused Ella.

This example highlights the role of the researcher in interpreting communication. The interpretation of the interaction between Ella and Nan presented is not necessarily the interpretation one would reach simply by reading the transcript of the stream of action. A more obvious interpretation is that Nan did not hear Ella and wanted her to repeat what she said. However, the interpretation followed months of observing in the setting. In this time it was clear that not only was Nan not deaf, but that this was a strategy she used time and time again to delay having to respond to ambiguous stimuli.

The analysis presented in the following chapters is based on my application of this framework to understand the communication of the older residents in relation to my particular situated understanding of the perspectives they brought

to make meaning in the setting, the context and what I captured of the stream of action. Thus understanding of the individuals was central to understanding their communication. In the following section the understanding that I gained of the residents whose communication forms the basis of the study is presented. The residents who feature most heavily in the analysis are introduced and an account of their perspectives and projects developed.

5.4 Introducing the residents In Elm View

Elm View was home to up to 42 residents at any one time, about half of whom had dementia. Over the following pages, the residents whose experiences feature most prominently in the analysis are described in detail, including: the perspectives they brought to make meaning of life in Elm View; their social relationships; self identities and the routines and rituals that they sought to engage in. It is important to clarify at the outset that although the experiences and perspectives of female residents dominate this section and the following analysis, I did not particularly seek out their experiences, merely included those residents with dementia who spent most times in the communal areas of the home. There were only three men with dementia in the home, all of whom were physically very frail and spent extended periods of time in hospital during the fieldwork and therefore escaped my gaze.

The importance of family was a perspective that many of the female residents in the home shared, who defined themselves first and foremost as mothers, daughters and wives. Beatrice was a lively resident in her late eighties for

whom being a mother and grandmother was central to her self-identity. She was very proud of the achievements of her son and often spoke about the important work he did overseas. Even though they lived in the south of England, Beatrice's most important social relationships were with her family who came to visit regularly and called her on the phone. She was most excited that her grandson was coming to university in the city and had promised to come and see him often. Beatrice was a very sociable woman and although her social relationships with her family were of the greatest importance to her, she had also developed a number of social relationships with residents and staff in the home and had very much embedded herself in the community of Elm View. Beatrice's routine, when she was not in too much pain from arthritis, tended to centre round the organised social activities in the home such as the craft group.

Lena who was from Eastern Europe, also identified herself primarily as a mother and spoke often of her pride at the good job her son managed to get when they came to Scotland after escaping the Russians, which was something she did not embellish on. She continued to have a close relationship with one son in particular who came to visit her regularly. Staff reinforced the importance of this relationship. On one occasion Mel the hairdresser commented to her 'I hope your son likes it (her hair cut), he gave me a good tip!' Despite speaking excellent English, Lena did not socialise much with the other residents. Instead she spent most of her time sitting in her chair next to Maureen a fellow resident in the 'red' flat who had a significant learning disability and had moved to Elm View from the hospital where she had spent most of her life. Maureen very

rarely spoke, restricting her day to day communication to either nodding or turning away.

As Maureen rarely spoke unless she was very upset, it was hard to discern her perspectives on life. One thing that it was clear she did value, however, was her relationship with another resident of the red flat, Stan. Stan and Maureen had developed a very close relationship, and were each others' key source of companionship, with neither of them having much contact with friends and family outside the home nor being embedded within broader social networks in the home. Maureen was always at her liveliest when Stan was around and whatever was going on would focus her attention on him. In return he would feed her chocolate and smile and giggle with her. Staff and some of the other residents, however, felt very wary about their relationship, which was subject to lots of scrutiny lest Stan attempted to kiss or touch Maureen in a way they deemed inappropriate. Maureen was a popular resident, whilst many of the male staff in particular felt uncomfortable around Stan and felt that he was taking advantage of the fact that Maureen had a learning disability. One staff member told me that she thought some of the fears of the other staff about the relationship were ungrounded and proudly told me that she let them spend time together in each others' rooms, adding 'as long as the door is kept open'. Stan felt this disapproval keenly and, as the following excerpt of data shows, worked both to formalise their relationship whilst avoiding 'trouble', such as being described as a paedophile by another female resident in the flat.

When I video recorded Stan, Lena and Maureen together in the lounge of their flat, Stan asked if he and Maureen could be recorded just the two of them. Stan moved his chair to be closer to Maureen and the two residents sat looking at each other, half smiling. However as Virgina walked in Stan frowned and turned to me saying, 'I'd better move or I'll be getting into trouble.' As he moved back Virginia turned to me and said 'It's disgusting, look at her picking her nose, and he's nothing but a dirty paedophile, always touching her up.'

The depth of feelings Maureen had for Stan really became apparent when he spent some time in hospital. It was not clear if she knew where he had gone, but whilst he was away Maureen sat in the foyer (a place I had never seen her during the previous eight months of fieldwork) waiting for him to return extremely agitated and upset. It was quite heartbreaking to observe.

Family was also important to Ella, who primarily identified herself as a daughter. She often spoke of needing to 'get away home to see my mother' or to visit her in hospital and of how good her parents were to her. At other times, however, she recognised that her parents and other family she had grown up with had died and grieved for them. On one occasion she retorted to Jean 'you'll no talk about my mother like that, my mother's dead!' and later cried to a member of staff 'oh my auntie's gone, she was an awfy good woman, I used to do the shopping for her.' Given Ella's attachment to her family it was striking that the only pictures she had of family in her room were of her husband and her cat. Although she spoke of her cat from time to time, Ella never mentioned her

husband and seemed to be ambivalent about her daughter with whom she had had a difficult relationship before moving into the home. Ella would sometimes ask when her daughter was coming to visit, but never spoke about her as a person. This distance she felt from her daughter was reflected in her response to Jean's question:

> J: we're talking about family affairs, how many bairns do you have?
> E: Oh don't start that for god's sake (gestures her to get away with her hand). I've nae bairns now, they're all away.
> J: what did you do with them?
> E: I never done nothing, (exasperated) they were all taken away, they were all taken away on holidays!
> J: Where to?
> E: No me! No I didnae go away on holidays. I never see the bairns now, they're all away.
> J: Aye

Ella was also a very sociable woman who joined in all the organised activities in the home and spent lots of time in the public areas of the home chatting to other residents. A key manifestation of Ella's advanced dementia was her disorientation and she spent lots of energy trying to get home. She would also tell vivid stories about the dangers she had encountered on trips out of the home which generally featured witnessing violent incidents and men in positions of authority telling her to 'get home to bed', or to 'get home and have a sausage'. The care home manager, Yvonne, suggested that these stories

stemmed from her experiences living by the docks during the war which had been a very rough area that had been bombed on many occasions.

Nan was another resident who came from a very working class background, but for whom the value of family was an important perspective. Nan had been one of 13 children, the rest boys, and had spent several years in a children's home when her mother was ill. Like Ella, she never mentioned her own children but spoke often of her 12 brothers and their various careers and achievements. Several of her brothers had died serving in the navy during the Second World War and she had pictures of their ships on her wall. The difficult experiences Nan had encountered over her life seemed to have led her to develop an acceptance of, and resignation to the strange and unfamiliar events that unfolded in her life. Although often Nan knew where she was, on other occasions she would ask repeatedly 'where is this place we are?' When she was told that she was in a home for older people, her key concern was not that she was in a care home per se, but that the location of the care home was not 'her place'. Thus for Nan belonging was important, as the following field notes show.

> Nan asked me where she was, and I told her Elm View, home for older people in (name of district), on (name of street). Then she asked how she came to be in such a place. I told her that because of her memory problems she needed looking after some more. Nan agreed and seemed satisfied with the explanation and told me that

she had been living by herself in (name of her district). Then she said that she had no idea what she was doing in (name of this district) as it wasn't her place. When I asked her if she liked it she said that it was nice enough, she had worked in the houses here as a cleaner, but that it wasn't her place, she was from (name of her district). Then she said that there were a different class of people in this area, or so they thought, though she didn't think that they were really any better.

Nan came to Elm View with a strong sense of both her own social location, as a working class woman, and the perspective that people from different social classes and / or geographical locations were different and that she did not belong with them. Nan was not alone in relating social or geographical location to a sense of belonging. For example Elsie and Geraldine found an immediate mutual affinity when they realised they both came from the same very middle class district as Elm View, as the following except of video recorded conversation shows.

Geraldine and Elsie are sat in the lounge of their flat and have been chatting closely together for a while when Geraldine says to Elsie.
G: (to E) where do you come from dear?
E: (name of district)
G: (brightly) I live in (same district)
E: do you! Where abouts?
G: Petrie Lane

E: very nice. I'm Bluebell Avenue

Elsie and Geraldine's shared geographical location immediately brought them together, indeed the use of the phrase 'I'm Bluebell Avenue' by Elsie intimately linked her own personal identity with that street. Geraldine and Elsie both lived in the same flat for a few weeks and in this time formed a strong bond with one another. Elsie was someone that few of the residents found easy to get along with as she was very disorientated and constantly driven to seek meaningful activity in the home, prompting her to go into other residents rooms. At times Elsie, who at 102 was the oldest resident in the home was very lucid and could 'pass' as having only mild dementia. Yvonne, the care home manager told me that she had managed to hide her dementia from the consultant psychiatrist who had been to visit shortly before I started fieldwork, and when I first met her had noted in my field notes:

> Explained the study to Elsie and she seemed to understand well and said that she was happy to take part, though she didn't want to keep an information sheet.

The other residents in her flat recognised that she was an exceptional woman as Moira commented 'she drives me to distraction, always coming into my room, but she can still count and spell, she must have been a powerful woman in her day' but were endlessly frustrated by her. Geraldine, however, did not seem to be bothered by Elsie's confusion and instead saw the person behind

her, at times, strange behaviour. They would engage in very empathic and mutually supportive interactions that visibly calmed Elsie down and helped Geraldine, who had recently moved into the home, to come to terms with her new situation and continue to feel useful, as the following clip of a video recorded conversation between them shows.

> Elsie and Geraldine are sitting close to each other holding hands and chatting. Elsie mumbles something about her room
> G: You want to know about your room, you're just opposite me dear, I'm in E5.
> Elsie looks at her
> G: if you ever feel that you want someone come and find me
> E: thank you, aye, aye.

Unfortunately this relationship was ended when Elsie was moved to a different flat as the staff feared that she would fall down the stairs.

One resident who clearly felt she 'belonged' somewhere far away was Maria who was from South America. Maria constantly spoke of how nice her home city was, that the sun always shone and that everybody there, like her, liked to sing and have fun, and therefore was very different from dull and grey Scotland. This sense that she belonged somewhere else was very important to Maria and like Nan was based not just on geographical location, but also social location. Maria's father had been an important government official and she felt herself to

be a different class of woman to the others in the home. As she commented one day:

> I hate the sewing and all the parts of the woman; I like to pass a good time. I have always had enough money for someone, and I prefer that.

Maria's determination to identify herself as different from the other residents made it hard for her to develop social relationships in the home. Maria received occasional visits from her children and people from the church who brought her communion, which was very important to her. Indeed both her faith and being a good mother were central to her self-identity. She also seemed to value the time that I spent with her and saw an affinity with me that she did not share with the other residents. Maria also often spoke of the fact that she had attended 'seven classes a day' before coming into the home and therefore appreciated learning. On one occasion she commented to the camera when I was chatting to her and recording:

> M: I like you yourself very much, I find us very similar. I will miss you when you go as I find you so similar to me in many things, and my birthday is in august and maybe that is why we are so similar, and so I am very happy. (I can't understand much of what she says after this as she jumps from talking about me to religion before finishing) there is two that come and one with the communion, so I am very happy.

Maria's key companion in the home was Rene who had the room next door to her. They both spent time in the shared lounge of the flat and would watch television and chat together. Rene was very socially aware, considerate of the needs of other people and valued good manners and hated boastfulness and pretensions (something that possibly came from being in service to an upper class family when she was a young woman). She found Maria's constant talking hard to live with and often told her off for being rude. The following excerpt of field notes provides an example of a very typical conversation between the two of them.

Rene and Maria are watching a Doris Day film when I come in and sit down and chat with my notebook out. Maria asks where I have been and if I am married. Rene tells her not to be so nosy. Maria wants to know if I prefer British or American men. Rene tells me that I have plenty of time to get married and tells Maria to be quiet and let them hear the film. Maria then tells me that she likes to be up [happy] (mimes it), no time for knitting (mimes it again) and that knitting isn't fun in South America. Rene tells her to be quiet about South America, they've heard enough, and to leave me alone to get on with my writing.

The importance of work was a further perspective that several of the residents shared. Elsie had grown up on a farm and spoke of being up at five in the morning to milk the cows, reflecting, 'it was hard work, but a good time'.

Similarly, Lizzie commented that she would still be working at the laundry if she had not been forced into retirement. Lizzie was in her mid nineties and as well as having dementia had a mild learning disability. She had never married but had lived with her brother until he had died. For Lizzie, work was central to her self-identity. The work ethic these women shared manifested itself in different ways when they moved into Elm View. Lizzie gained a lot of satisfaction by keeping busy making morning and afternoon tea for 'her ladies' as she referred to the women who shared her flat. This task not only preserved Lizzie's sense of self-determinacy but also provided an opportunity for her to interact with her fellow flatmates in a meaningful and yet well-structured and easily manageable way. Elsie however often experienced what Reed-Danahay (2001) termed 'dislocation', believing she was still at the farm, which left her constantly anxious and frustrated that she had no way to perform tasks like making tea for her sons and feeding the hens, hence her constant search for meaningful activity.

The final resident with dementia who featured heavily in life in Elm View was Jean. Jean had moderate dementia and had been an alcoholic, which had led to her move to the home. She had one son whom she spoke to every week, her other son had died a few years ago. Jean was keenly aware of her low social status as an older person living in a care home and was deeply fearful of the dementia she was developing, but rarely acknowledged. Thus, maintaining a positive self-identity as someone who was at the centre of things, able and who had self-determinacy was very important to Jean. She was very sociable and joined in all the organised activities in the home, but also sought to control

them, as the excerpt of video presented in section 4.4.3 that showed her acting as a kind of director for the video, calling people into shot demonstrated. Jean could be very confrontational, as evidenced by the conversation between Jean, Ella and Nan presented in section 5.0, and would often challenge the other residents and seek to boss them around. She liked to shock and would talk openly about sex, going to the toilet and her need for personal care. It was also important to her to have strong social relationships in her flat, the green flat, and had adopted Mary Peters as her 'pal'. Mary Peters was a relatively timid woman with mild dementia, who had moved to Elm View recently as her house had been condemned due to subsidence. At first Mary had felt quite bullied by Jean who tried to tell her what to do and get her running around after her, but in time had learnt how to handle her and the two women had developed a good friendship.

Jean's strong character, sociability and awareness of the low social status of the residents in society meant that she was an excellent informant in the study. She challenged the residents in the home, asking the questions that as a researcher, intellectually I would have loved to have asked but felt it would have been cruel to do so. In so doing, she brought all the negative cultural discourses in society around ageing, dementia, disability and institutionalisation described in chapter two and threw them into the faces of the other residents, whilst seeking to avoid them herself. It is unsurprising therefore that Jean's voice and actions feature heavily in the subsequent analysis.

5.4.1 Reflections

This introduction to the older residents with dementia in Elm View who are featured most in the analysis has highlighted what a diverse group they were. Residents differed in terms of: their past experiences; the perspectives they brought to make meaning in the home; their sense of self identity; social relationships and what they sought to do every day. Thus these findings support the emphasis within the field of dementia on 'person centred care'. The diversity of the residents in terms of the perspectives they brought to make meaning in the setting meant that different residents made very different meanings of the same things within the setting. Within this diversity, however the residents all shared one thing in common, the experience of being an older person living with dementia in an institutional care setting. The meanings the residents made of this aspect of their experience and the ways in which they responded to these meanings are explored in the following chapters.

5.5 Approach to understanding communication presented in this thesis

This chapter presents a framework for understanding the communication of the older residents with dementia in Elm View, and a number of concepts for interpreting the meanings they made in their streams of action and their responses. The framework outlined in this chapter has highlighted that the perspectives and projects of the older resident communicating intimately influence communication as well as the context and stream of action in which they interact. Thus, the understanding of the communication of the older

residents with dementia presented in this study is grounded firmly in their experiences and represents a departure from previous research on communication and dementia which has been based, however, loosely on the deficit model of dementia. The account of the residents presented in this chapter reflects this shift in emphasis, as dementia is identified as just one of the many aspects of their lives influencing their communication.

This thesis seeks to understand how living with dementia in a residential care home influences the communication of the older residents. As has already been highlighted, the framework used to understand this process was developed over the course of the analysis. Analysis of the data highlighted the need to understand the communication of the older residents symbolically, in relation to the meanings they made in their interactions. In so doing the thesis makes a significant contribution to understanding the communication of older people with dementia. However over the following chapters analysis is presented that highlights how the communication of the older residents with dementia was influenced materially as well as symbolically. In chapter three it was argued that society is more than symbolic interaction. This was very much the case in Elm View, where observations of the older residents revealed that the context in which they lived influenced the kinds of interactions they had and indeed the kinds of stimuli they encountered to make meaning of.

In chapter two it was argued that examining the experiences of older people with dementia in relation to their experiences of marginalisation and exclusion

was vital to advancing understanding of dementia. Over the following two chapters the framework outlined in this chapter is used to examine the communication of the older residents in relation to both their experiences of their context and of marginalisation and exclusion. Specifically the meanings the older residents made of the societal and institutional facets of their context, as described in section 5.2.1, are examined and the ways in which they responded to these meanings through their communication explored. In so doing the thesis considers the influence of these facets of context on the communication of the older residents with dementia.

In chapter six the interactions the older residents had with and within the societal facet of context are examined. Specifically the meanings they made in interaction with this context of three key aspects of their experience are examined. These are; living in a care home, being old and having dementia. The chapter examines how the meanings the residents made of these aspects of their experience in interaction with the societal context shaped both their communication and their experiences. In chapter seven the interactions of the older residents are examined in relation to the specific institutional context of Elm View. The meanings the residents made of the institutional facet of their context are interpreted and the impact of these meanings on their projects explored. Furthermore, the ways in which the communication of the older residents was influenced by the context as experienced materially by them are considered.

Through examination of the communication of the older residents with dementia in this way, the thesis elucidates the ways in which living with dementia in a residential care home influences communication. Furthermore, the analyses reveal some of the ways in which processes of exclusion and marginalisation operating at societal and institutional levels are reproduced in the home and influence the communication of the older residents. In so doing the thesis makes a considerable contribution not only to understanding communication and dementia but also to understanding the experiences of older people with dementia in residential care.

5.6 Conclusion

Over the course of this chapter, a framework for understanding the communication of older residents with dementia living in residential care has been presented and the older residents on whose communication the study is grounded are introduced. The framework outlined for understanding communication in this study draws broadly on a symbolic interactionist perspective, but was developed over the course of the data analysis. Central to this framework and the approach to understanding communication is recognition of the dynamic, circular and interwoven nature of communication within social life. Thus the framework presented is not purported to be the way to understand communication, but instead constitutes a set of concepts through which to unpack the interactions of the residents and a framework on which to build understanding.

The chapter identified two key processes underlying communication, meaning making and responding, occurring across five phases of interaction. Three key factors were identified that influenced the meaning making process. These were: the context in which the interaction occurred, the perspectives of the resident interacting and the stream of action. However, the interwoven and nebulous nature of all three factors was highlighted alongside the particular challenges for research seeking to interpret the meanings the older residents made of stimuli encountered in their streams of action. Furthermore, the process by which the residents responded to these meanings was elucidated. The three phases of response were outlined and projects of the residents described.

The development of this framework for understanding communication makes a key contribution to understanding the communication of older people with dementia living in residential care. The framework looks beyond what is said and done in interactions to examine communication in relation to the perspectives of the older residents themselves and the context in which they live. Furthermore, examination of the meanings the residents make of institutional and societal facets of context in relation to their projects makes an explicit frame through which to understand the relationship between experiences of social exclusion and marginalisation and communication. This is central to broadening understanding of dementia as well as communication and dementia.

Finally, the framework focuses on the perspectives of the residents and the ways in which the projects of each individual are manifested. In so doing, the framework puts them at the centre of the understanding of their communication and looks at them as people with a rich history of experiences governing communication first, and people with dementia second. Indeed examination of the residents whose communication forms the basis of this study revealed that the residents in the home were very diverse. They came to the home with a range of perspectives shaping the meanings they made in the home and with very different expectations and beliefs about the kind of self-determinacy and social relationships they wanted to maintain in the home. Furthermore the self-identity of the residents was grounded in a wide range of experiences for example being a mother and a daughter; being working and upper class; being a good worker and being sociable.

Over the course of the following two chapters the ways in which the communication of the older residents was influenced by their experiences of living in a care home, being an older person and having dementia and by the specific institutional context of Elm View are examined in detail.

Chapter 6

The influence on communication of living in a care home, being old and having dementia

6.0 Overview

This chapter explores the ways in which living in a care home, being old and having dementia influenced the communication of the older residents in Elm View. Specifically, the chapter examines the meanings the older residents made of each of these aspects of their experience in relation to the societal facet of the context in which they lived and the ways in which they responded to these meanings through their communicative acts. An account is developed of both the ways in which these meanings impacted on the projects of the older residents and the ways in which the residents negotiated their projects in relation to these three aspects of experience. Furthermore, the chapter examines the ways in which living in a care home, being old and having dementia influenced the communication of the older residents in more material ways.

In section 6.1, the meanings the residents made of their experience of living in a care home are examined. In section 6.2, the ways in which the residents responded to their experiences of both being an older person and being frail are

considered. Finally, in section 6.3, the three distinct ways in which the residents experienced dementia, and how these influenced their communication are explored.

6.1 Living in a care home

Living in a care home was an experience that all residents shared and were forced to make meaning of through their interactions with and within the societal context. The review of the literature in chapter two revealed that living in a care home is a problematic experience for older people with dementia (Bland, 1999). Not only is institutionalisation stigmatised by society, but also the prospect of moving to a care home is regarded with fear and dread by older people (Peace et al, 1997). Furthermore, institutionalisation and the presence of institutions has been shown to perpetuate the marginalisation and exclusion of older people (Townsend, 1981). Analysis of the data revealed that many of the older residents in Elm View shared these views of institutionalisation and that negative discourses around living in a care home, in the societal facet of context, influenced the meanings the residents made of living in the home and themselves and others in the home.

Analysis of the data revealed that when the residents made meaning of their experience of living in a care home they interacted with the societal facet of their context and made meaning in relation to two problematic experiences. The first was that they were expected to respond to Elm View as 'home', although they did not feel it was their home. Secondly, living in a care home was a

constant reminder of the circumstances that led to their move to the care home. The ways in which residents responded to these threats, and through their communication, sought to mediate the impact of these threats to their projects, are described over the following pages

Home was an important concept for all the residents, and one meaning that they all shared about Elm View was that it was not their home, as reflected in this conversation between Geraldine and Elsie.

G: you're better here though dear where you get looked after

E: but you see this isn't my home

G: it's your home now dear, and you're best to make the best of it.

E: I'm not

G: what dear?

E: I'm not making the best of it.

G: no (sighs empathetically)

Residents reached different understandings as to what the place was that they were in. Many residents like Geraldine were very aware that they were in a care home, however other residents such as Nan and Ella were often confused as to where they were. It was clear from the findings that whether or not the residents knew where they were, they did not experience the existential feeling of connectedness, essential to Jackson's (1995) definition of home. This was reiterated through the language they used to describe where they were, most commonly referring to it as 'this place'. For example, Jean said 'I never thought

I'd end up in a place like this'. Nan asked 'where is this place we are?' and Ella telling me 'I have to get out of this place with these people and get home'. Thus although the residents knew that 'this place' was not home they were often unable or reluctant to name what it was, an institutional care setting for older people. Residents, however, varied in terms of what home did mean for them. For Maria, home was the city that she had grown up in, even though her children were in Scotland. For Ella and Mary however, home was the last house they had lived in, as Mary said:

> 'I wish I could go back, but only to my old home, however it's not there anymore. My son tells me to forget about it. It's not the same here, but I make do.'

These excerpts of data illustrate well the ways in which the meanings the residents made of being in a home threatened their projects. Jean's comment that she never thought she would end up in a place like this clearly shows how being in a home impacted on her self-identity and reflects the view of institutions more generally in society as places where 'others' live. Similarly the threat of being in a home to Ella's project of preserving social relationships was evidenced by her wish to get away from 'these people' and back to her family. Furthermore the comments of Mary and Nan reflect how being in a home both threatened their self-determinacy directly and reflected their lack of self-determinacy generally. Nan's confusion as to where she was meant that she could not possibly have determinacy over what was going on around her. For

Mary, being in a home was a constant reminder that she no longer had a say in where she lived.

Residents responded to the threats to their projects of the meaning they made of 'being in a home', as not home, in two key ways. Some of the residents, in particular those with more advanced dementia such as Ella and Elsie, resisted the meaning that this was somewhere they should stay and constantly sought to leave the home. Ella, as we have already seen, wanted to get to her parents home. Elsie however, just seemed to want to get to a place where she might find some kind of fulfilment and thus seemed very much to engage in the search for an experience of existential connectedness. Most of the residents, however, like Geraldine and Mary, recognised that they were in the Elm View for the rest of their lives and sought to make 'the best of it'. In this way, they accepted the meaning that although it was not home, this was where they were to stay but they responded in ways that sought to preserve their projects despite that. By making the best of it, the residents showed resilience, bolstering their self-identity. Furthermore by constructing an active role for themselves in shaping their future in the home, the residents were able to preserve some self-determinacy.

The rhetoric in the home about making the best of it was powerful, supported by both staff and other residents. Residents who did not buy into this response to being in the home were constructed as a threat to the community and given short shrift, as the interchange between Jean and Ella in section 5.0 showed.

Even the most gentle of residents could be caustic towards other residents who refused to put on a brave face as the following excerpt from my field notes shows.

> One day Yvonne, the manager, introduced to Jean and Rene a new resident who had just been dropped at the home for the first time by her daughters and was sobbing that she had been abandoned and didn't have a home any more. After being sympathetic for a minute or two and trying to comfort her, Rene snapped, 'we don't have a home any more either, and we've got used to it'.

Residents moved into Elm View for a plethora of reasons. However, many of the residents in Elm View were there because they were either single, or their social relationships had broken down due to divorce or losing contact with family members. This is not surprising given that the care provided in Elm View was such that many people with similar needs were supported in the community and is consistent with previous research which found a high proportion of divorced, widowed and single people in residential care homes (Wilcocks, 1987). This had particular implications for the meanings the residents made of living in a home, as many of the residents had faced threats to their self-identity, self-determinacy and social relationships before moving to the home, which were exacerbated by their move to the home.

Research reviewed in chapter two highlighted the traumatic nature of the move into a care home, especially when the resident did not understand what was

happening to them (Chatterji, 1998; Reed, 1999). These findings were echoed by the experiences of the older residents in Elm View who struggled to make meaning of their move into the home. For many residents, the move into the home was the final manifestation of their growing exclusion and marginalisation. Many residents were unwilling or unable to talk about the circumstances around their move, constituting as they did, possibly the ultimate challenge to their self-determinacy. Jean however sought to negotiate this challenge telling me that 'she had just moved in to see how she would get on'. She then asked if there were other 'places' nearby and when I said that there were, but that I didn't know what they were like she said 'well I don't have time to go looking at other places anyway'. In this way, Jean negotiated the threat to self-determinacy posed by being in the home by constructing an account of her move into the home as something that she had had a hand in and that she could take control of again in the future if she had time.

Ella's account of moving into the home, however, reflected her feelings of helplessness and total lack of determinacy. She told me that she was here because her parents had abandoned her. She said that a man in a red car came to collect her and brought her here and that she hadn't seen any of them since. Thus her only response to this threat to her self-determinacy was to try to leave and make her own way home, which she sought to do most days. Ella's experience and response was very similar to that of Mr R documented by Chatterji (1998) and highlights the importance of involving the person with dementia in the decision to move into the home.

An important way in which the residents responded to the challenges to their projects of the meanings they made of their move into the home was to construct a legitimate account of why they were there. Wilcock, (1992) highlighted that having family who refused to care was identified by residents as an illegitimate reason for moving into the home. This was also the case in Elm View and residents who had family were keen to reinforce why they were unable to look after them. Rene often spoke of her daughters and their new lives overseas and told me that although they had asked her to go and live with them, she was too old now, which was why she was here. Other residents told me that their children were too busy with their careers to look after them. However, this explanation did not wash with Jean. Jean felt strongly that had she had a daughter things would have been different, as the following field notes from a conversation I had with her show.

> Jean and I are sitting in the foyer chatting. Jean asks me if Ella has a family and I say she has a daughter. Jean says 'well what's she doing here if she's got a daughter, I looked after my mother until the day she died.' She then went on to tell me that she had no daughter to look after her, just a son who lives in England. His wife isn't going to look after her, and she doesn't want to be a burden to them. She then reiterates that daughters don't look after their parents these days; they put them in a home. I suggested that it's maybe because more women work to which she replied that she would have looked after her mother just the same.

It is clear from these findings that the meanings the residents made of being in a care home challenged their projects of preserving self-identity, self-determinacy and social relationships. These findings support Peace et al's, (1997) reflections that the key to improving care homes is to find ways to overcome the threat to the self of the residents. As Peace and Holland (2002) found, none of the residents would have chosen to come to Elm View, and many were not even involved in the decision. The findings show that the meanings the residents made in interaction with their societal context were powerful and residents felt the stigma of 'being in a home' keenly, as evidenced by comments like 'I never thought I'd end up in a place like this'. This meant that it was hard for the residents to resist both the fact that they were in the home and the threatening meanings they made of being in a home. Many residents accepted that their self-identities were now anchored to 'being in a home' and sought to integrate being a resident into their self-identity in a way that minimised disruption to it. Residents who acquiesced and accepted this anchoring responded by developing accounts of needing to make the best of being in a home and of the legitimate reasons for their institutionalisation. Other residents, however, resisted this anchoring and through their responses day after day, month after month, refused to accept that this is where they were to stay.

Living in a care home also impacted on the projects of the residents of preserving social relationships. For residents who did still have friends and

family, being in a home meant very real and physical exclusion from them. Despite the accessible location of the home, relatively few residents in the home had regular visitors and residents were dependent on family and friends to get out of the home to make visits. The residents responded to this challenge by publicising visits when they did occur and talking about trips out for some time afterwards. This was something that staff and other residents in the home supported, reminding residents that they had had visitors or making a point of asking them about their trips out. These findings echo those of Gubrium (1975) and Reed et al (1999) who both highlighted the importance of visitors to maintaining social relationships and self identity on moving into a home. Not only did being in a home hinder residents' maintenance of existing ties, it also limited residents' opportunities to make new relationships to within the boundaries of the home. As chapter five showed, the residents in Elm View were a diverse group and only a few residents found people that they could form new and lasting relationships with. Furthermore as the cases of Stan and Maureen and Elsie and Geraldine show, these relationships were always at the mercy of the staff and decisions made regarding running the home. These issues are explored in more depth in the following chapter.

These findings show the ways in which the experiences of the residents, of marginalisation and social exclusion, were reproduced when they sought to make sense of their experience of living in a care home. However, the findings also illustrate the ways in which many of the residents were able to work to negotiate these experiences of marginalisation and exclusion through their

interactions with the world. Furthermore, the data analysed in this section also illustrates clearly the extent to which the three projects overlapped and in particular, how a challenge to the self-determinacy or social relationships of the residents also challenged their self-identity. Asserting a positive self-identity was an important means used by the residents to respond to threats to self-determinacy or social relationships.

The experiences of the residents of being in a care home and the meanings they made of this influenced their communication in several ways. The first and most concrete way in which it influenced their communication was by physically limiting their opportunities for interaction to those people in the home, or already within their social networks. Being in a home, however, also influenced the communication of the residents by threatening their projects, in particular of preserving self-identity. As the findings presented showed, residents responded to this threat in two ways, either by resisting or more commonly making the best of it. Indeed, residents worked together to make the best of it and supported each other to this end. However, resisting was a very solitary enterprise and one that got no support from either fellow residents (even fellow resisters) or from staff. The consequence of this for the communication of the residents is explored in more detail in sections 6.3.

6.2 Being old

Review of the literature in chapter two highlighted the extent to which being old is feared and construed as a problem by society. Not only are older people

systematically denied access to resources (e.g. Estes et al, 2001), but are also feared and marginalised by a society that values youth (Featherstone and Wernick, 1995). Furthermore, the frailty that many older people experience has led to their embodiment by society perpetuating their exclusion and marginalisation (Harper, 1997). In these ways, societal discourses around ageing serve to threaten the projects of the older residents, and in particular their project of preserving self-identity. As highlighted in section 2.3, the ways in which older people experience these threats has been conceptualised in different ways, with ageing said to be experienced as a stigma (Matthews, 1979) and as a mask (Biggs, 1999; Featherstone and Hepworth, 1991; 1995). Over the following pages, the meanings the older residents made of two aspects of their experience of being old are examined and the ways in which these impacted on their projects are explored. These are of being an older person and frailty.

6.2.1 Being an older person

Analysis of the findings revealed that, when the older residents in Elm View sought to make sense of and negotiate their experience of being an older person, they interacted with negative societal discourses around ageing and broadly accepted them. The language the residents used to describe themselves and other older residents reflected negative stereotypes of older people. Residents referred to each other and themselves as 'old dearies', 'old folks' and 'pensioners'. Furthermore, they embraced the view that older people were boring to young people; as Maria asked me, 'why you come here with all

these old people? You so young to spend time with us old people?' However, although the residents accepted and embraced negative discourses around ageing, they were able to negotiate the impact of these meanings on their projects. The residents engaged in two key strategies to this end. They worked together to construct a positive account of being an older person that emphasised wisdom, endurance and achievement. Furthermore the residents worked to counter negative aspects of old age by asserting their youthfulness, attractiveness and sexuality. Analysis of the data revealed that these strategies overlapped, with residents working to highlight their experience and youthfulness at the same time.

Despite the negative discourses around being old, many of the older residents considered living to an old age as being an achievement and one that afforded them status in the home. In particular, residents who maintained a youthful outlook and appearance into advanced old age were celebrated in the home, as the following excerpt of conversation between Nan and Jean showed.

> Nan: How old are, you if it's not impertinent?
>
> Jean: 86
>
> N: that's a good age
>
> J: what are you
>
> N: 92
>
> J: (turns to me a nods impressed) 92!

Age was a common topic of conversation, and the oldest residents in the home bolstered their self-identities by disclosing to others just how old they were. For example Geraldine said 'I'm 94 you know', to which I responded as expected 'Gosh, you don't look it'. In particular, Elsie, who was over a hundred and the oldest resident in the home, was responded to with awe and respect by staff and other residents in the home.

Being old was not just about age, but was also about being part of a particular generation. In their conversations together, the residents differentiated themselves from 'people today' and reminisced about the difficult times they had lived through. In this way the residents constructed a shared identity as a generation of resourceful and resilient people. For example, in the craft room, residents would often share stories of their resourcefulness during and after the war. On one occasion, Heather, Moira and Beatrice told everyone how they had recycled cloth and wool from old curtains and clothes to make new clothes. Residents also worked to preserve a positive self identity by talking about the many achievements in their long lives, in both their careers and family lives and they readily gave advice to me and the care staff about relationship and family issues. In these ways, the older residents bought into the rhetoric of healthy ageing, that being old and acting young was an achievement.

The sexuality of the residents served as a key tool to assert an active and nubile self-identity, despite advanced age. Jean in particular, worked hard to emphasis her sexuality as the following excerpts from the field notes showed.

Mary and Jean are sitting in the lounge of their flat when I come in and start chatting to them. Almost immediately the conversation turns to sex and Jean complains that there are no men in the home. Jean turns to me and asks if I've ever 'done it'. When I sheepishly reply, Jean pulls a mock scandalised face and Mary laughs saying 'take no notice of her, she's got a tongue ye long' indicating with her hands. To which Jean jokes 'I wouldn't mind seeing a man that was ye long', again indicating with her hands the size of a penis. We all laugh and Mary says 'she's an awfy woman, but a good pal.'

In Jean's account of her sexuality, it is certainly not age that is holding her back from acting out her sexual desires but the lack of men in the home. Members of staff and other residents reinforced this perspective, for example, Fiona, the activities leader, asked her one day 'Jean, if you had a man what would you want to do with him, where would you like to go?' It was almost as though Jean wore her sexuality as a badge of honour and on one occasion quite cruelly put a fellow resident Jennifer down saying 'she's a virgin, you're a virgin aren't you Jenny.' On another occasion, however, Jean did concede that her old age might hold her back sexually. When Ella teased her that a day care attendant who kept walking past them was looking for someone to make love to, Jean replied 'He'd have to do all the work!'

Although Jean was more overt than other residents, she was not the only one to assert a sexual self-identity. Maintaining an attractive physical appearance was

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important to lots of the women in the home who all visited the hairdresser and many of whom wore make-up. Residents also defined themselves sexually through talking about their married lives and were quick to offer me advice on relationships. Some of the female residents also engaged in flirting and sexual banter with male staff and visitors to the home.

> Beatrice is sitting in the foyer chatting with other residents having just had her hair done, as Jim, a care worker walks past, Beatrice calls out to him.
>
> B: I'm all poshed up for you Jim
>
> J: and you're looking gorgeous
>
> B: I'm all poshed up for you Jim
>
> J: and you're looking gorgeous

Many of the male residents in the home also took care over their appearance and sought to maintain an identity as a sexual being, indeed gentle flirting was characteristic of lots of my interactions with the male residents in the home. For example when I was sat in Peter's chair chatting to another resident and made to move when he came in, he joked, 'don't move, I was just going to sit on your knee'. This finding supports other research carried out in institutional care settings that showed the older residents expressed themselves sexually in a range of ways (e.g. Archibald, 2002; Hubbard et al, 2003 (see Appendix G).

These findings on the meanings the older residents made of being old challenge the extent to which the residents experienced ageing as a stigma.

Although they were aware of negative discourses around ageing, they were able to draw on many resources both collectively and individually to maintain a positive self identity. Being old did challenge their project of preserving self identity, however the influence on their communication was generally positive, with residents acting and interacting together to preserve their positive identity. Furthermore, in the context of Elm View, the meanings that the residents made of being old did not challenge the projects of the residents of preserving self-determinacy or social relationships. These findings support Featherstone and Hepworth's (1991) conceptualisation of ageing as a mask, influencing how older people are seen as opposed to how they see themselves.

6.2.2 Frailty

The frailty that many of the older residents experienced, and that accompanied their old age, posed a greater threat to their projects than being an older person did. Indeed, the efforts of the residents to present themselves as attractive, sexual and active, acted as somewhat of a double edged sword, as the frailty and resulting disability that many of them experienced could not be accommodated into this healthy ageing rhetoric. Residents struggled to come to terms with their growing frailty and the impact it had on their self determinacy as the following conversation between Geraldine and Elsie reflects:

> G: you're tired aren't you?
>
> E: I om, I get tired easily (Nods her head slowly)
>
> G: I know you get tired quite easily don't you

E: and I don't understand it

G: it's your age dear

E: oh I never thought about that (sounding genuinely surprised)

G: we don't grow any younger dear

E: oh no no no, (agreeing, then looks down and shakes her head)

Residents bemoaned the many things they could no longer do, such as walk to the shops or have a stroll in the garden for fear of falling, or because they were too weak. As Jennifer reflected, 'if only I could get up the road to the shops, but I'm too slow now'. Thus frailty presented an extra challenge to their projects of preserving and creating social relationships and self-determinacy. Frailty also had a profound impact on the self-identity of the older residents, in a way that ageing alone did not. The self-identities of the residents were very much anchored by their frailty, which in turn restricted their sense of self-determinacy. Thus they were unable to resist the impact of their frailty on their self-determinacy, social relationships and self-identity. The older residents found it hard to see past the barriers that their frailty presented to doing the things that they wanted to do, such as go on trips into town or even just walk in the garden. On one occasion, Peter had declined to go on a trip to town, and it transpired afterwards that it was because he felt he was too heavy for anyone to push in a wheelchair and had not thought that they might have gone in a bus. Similarly Beatrice commented:

Beatrice: I would just love to go to (local sea side district), its lovely there,

J: well you can just get in a taxi and go for the day

B: I didn't think about that

J: it's not much to want is it, to go to (local seaside district)

These findings are in contrast to research into the experiences of younger

people with disabilities, many of whom were able to construct a self-identity not

tied up with their disability and saw impairment as just one part of normal life to

be got on with (Watson, 2002). However, frailty was not normal for the residents

in Elm View, the vast majority of whom had lived lives relatively free of

impairment, but when experienced as an older person living in a care home it

squashed their sense of self-determinacy and dominated their sense of self-

identity. Furthermore, these excerpts of data highlight just how excluded the

older residents were. However, all of the residents attributed the restrictions in

their lifestyle to their frailty. They did not recognise the structural and cultural

processes that led to their needs being met in an institutional care setting as

opposed to in the community, and that exacerbated the impact of their frailty on

their self determinacy and social relationships. Only one resident explicitly

acknowledged their excluded and marginal position in society, when she

muttered in response to a TV news report 'don't talk to me about bed blocking'.

Foucault (2001), in his discussion of technologies of the self, argues that before

people can resist processes of subjectification they need to recognise them.

These findings show that the residents in Elm View were unable or unwilling to

explicitly acknowledge their profound experiences of marginalisation and social

exclusion and thus were a long way from acting to resist them at a societal level.

Elias (1985) highlighted the extent to which death is swept under the carpet in modern society and this was reflected in my interactions with the residents. The only resident who talked about the prospect of her own death explicitly was Elsie. One day, frustrated that none of the carers were heeding her requests to get chops for her son's tea, she reflected 'I don't ask much of life, just a bit o' meat. I just sit here waiting for darkness to come, what kind of a life is that?' Elsie then talked profoundly about being 'done in', 'tired' and that she was just 'waiting to die'. When I asked her if this worried her, she replied 'no, not for me, just for everyone else.' Death clearly did not pose as much of a challenge for Elsie as living with dementia in Elm View did.

The analysis presented in this section highlights the impact of physical frailty, over and above that of ageing on the lives of the older residents in the home and their projects. Although residents were able to act to construct a positive self-identity despite their old age, they were less able to maintain this identity in the face of their frailty and its impact on their self-determinacy in particular. These findings support the warnings about the possibilities for older and disabled people to reinvent themselves in post modern society reviewed in chapter two. (Featherstone and Wernick, 1995; Hughes, 2001; Laws, 1997; Tulle-Winton, 1999), and highlight the need for the development of cultural discourses that accommodate frailty, disability and disease.

These findings show that being old influenced the communication of the older residents in a similar way to that which being of a home. Being old threatened the projects of the residents, in particular of preserving self-identity, forcing them to respond to these threats through their communication. However, many of the ways in which the residents responded to these threats were positive, often working together to construct old age in terms of wisdom and achievements and therefore preserve their self identity. Being frail, however, influenced the projects of the residents in more negative ways. None of the residents was able to resist the threat frailty posed to self identity, self determinacy or social relationships, and few even tried. In this way, frailty silenced the residents in a way that being old did not. Frailty was made meaningful by the residents as the reason for all their problems.

6.3 Dementia

Review of the literature in chapter two revealed that dementia is a problematic experience. Not only are people with dementia stigmatised (Bond and Corner, 2001) and faced with fear by society (Moran, 2001) but many people with dementia experience cognitive impairments that lead to communication problems (Bourgeois et al, 1991) and live in depersonalising care environments (Kitwood, 1997). Over the following pages, findings are presented that add weight to this overall picture of dementia, but also that highlight the complex interplay of factors determining how residents experience dementia and how dementia influences their communication.

Dementia was something that it was hard for the residents of Elm View to escape from. Approximately half the residents had dementia themselves and all the residents shared the experience of living with people with dementia. Analysis of the findings, however, revealed that the residents experienced and made meaning of dementia in three different ways, all of which influenced communication differently. These were: having dementia; living with people with dementia; and being identified by other residents as having dementia. The meanings the residents made of dementia in these ways and the impact of these experiences on communication are explored in turn.

6.3.1 Having dementia

Although half of the residents in Elm View had dementia, analysis of the field notes revealed that none of the residents acknowledged that they had dementia. Instead the residents with dementia viewed having dementia as just another form of frailty. Residents spoke openly about their memory problems, which were seen as being a normal part of life in the home, as Jennifer commented, 'I've got awful dozy since I moved in here'. Residents freely admitted to experiencing problems with their memory and would empathise with each other, for example, Jean told a carer that she knew that one of her sons had died, but couldn't remember what of. On another occasion, when I asked Rene and Beatrice how long they had lived in the home as they were sat in the conservatory, Rene responded 'it's funny we were just talking about that, we can't remember' and Beatrice finished 'I know, I can't remember, I can't

remember anything.' Thus dementia was experienced and made meaningful as a normal part of being old and in a home. Therefore the meanings that the residents made of their own dementia did not threaten their projects of preserving self-identity, self-determinacy or social relationships any more than the meanings they made of being physically frail. This finding presents a very different view of dementia from that presented by much of the dementia literature. Dementia did not entail a catastrophic loss of self for these residents (Orona, 1997), but instead the symptoms of dementia constituted an additional set of challenges to be noted and dealt with where possible.

As the literature reviewed in chapter two revealed, having dementia did influence the ability of the residents to make meaning and respond. Many residents with dementia would speak in incomplete sentences, change topics during conversations with no warning and experienced difficulties with word finding and with names. For example, Elsie looking at her wrist asked a fellow resident 'what times, what have you got on your clock?' Thus, at times it was quite difficult to follow the meanings some residents were seeking to convey. However, as the following example shows it was not just the older residents with dementia who experienced these kinds of communication difficulties

> As Jennifer walks past, the carer grasps her warmly by the waist to point her in the direction for tea, saying 'Carry on and to your left'. Jennifer's flat was actually to the right and she started to head into

the wrong flat until the carer realised her mistake and corrected her.

Despite the communication problems experienced by many of the residents, they were all still able to engage in meaningful interactions with others in the home. Residents were frequently observed to use non verbal communication in their interactions with each other. For example, Beaty and Iris, who both had advanced dementia and were close friends, would spend long periods of time in each others' company negotiating shared rituals such as lighting each others' cigarettes using purely non verbal communication. Other residents with dementia used gestures explicitly in the place of words. For example Ella pulled out a chair and pointed to it, encouraging me to sit down as I came into the craft room one day. On another occasion, Jean shouted out to a carer to come and help her and mimed pulling her trousers up. These findings support previous research highlighting the importance of non verbal communication to the communication of older people with dementia (Hubbard et al, 2002).

Many residents were adept at accommodating each others' communication problems, working round inconsistencies and moments of confusion, as the following excerpt of conversation between Geraldine and Elsie shows

Elsie and Geraldine are sitting next to each other, Elsie leaning right in and holding Geraldine's hand.
E: I've had a bad day

G: yes I know

E: I've had a bad, dad, day

G: yes we all have good days and bad days dear

E: well eh.. (trails off and shakes her head looking down)

They sit in silence for a few seconds and Elsie looks down and then up and says

E: eh its such a life, I would like to lie down for just quarter of an hour

G: well you go and lie down then dear

E: but my hair is all thingm'ed, achh I'm just up the stair and I'll bring Jonny, och

G: I know

E: Och

G: It's nice to have someone to talk to though, isn't it (strokes Elsie's hand)

E: Och aye (Elsie looks up at her and smiles and then looks away smiling).

In this conversation, Geraldine was able to see past the words Elsie was saying and respond to the general meaning she was conveying, thus supporting Elsie to talk about her experiences of ageing. In this way Geraldine supported Elsie's projects of preserving self-identity and social relationships. In this interaction Geraldine provided a textbook example of person centred care and illustrated that it was not just staff who had the skills to support the communication of the older residents with dementia.

Geraldine, who did not have dementia, was a quite exceptional resident in the home, particularly in relation to the patience she had with Elsie and her ability to engage with Elsie in a way no one else in the home could. However, she was by no means the only resident who worked to overcome the communication problems of residents with dementia in this way. Residents with dementia were also observed to help each other work round their communication problems as the following example shows.

> Beatrice, Jean and Mary Peters are sat together in the craft room and Alec (a male resident without dementia) and I are sat next to them with the video camera on behind me. Beatrice turns to Alec and says
>
> Beatrice: Mary Peters came into my room last night, it was two in the morning, I got into an awful state
>
> Fiona, the activities coordinator who is walking around behind them, corrects her
>
> F: It was Mary Mason, this is Mary Peters (puts her hand on Mary Peters shoulders, who is sitting next to Beatrice).
>
> Jean: Did you think it was Alec?
>
> B: No I knew it was a woman
>
> J: I lock my door
>
> Mary Peters then says: It wasn't me who was knocking on your door
>
> B: I don't know who it was; it was a woman, Mary Peters
>
> M: I'm Mary Peters
>
> F: that's Mary Peters
>
> B: it was Mary Mason, Mary Mason

Researcher: So what happened then Beatrice?

B: I had to go looking for Alec as Mary Mason was in my room, not Alec.

J: I lock my door

B: I'll lock my door too

R: so what did you do, how did you get her out?

B: she just walked round the room, (puts her head down) she goes into your drawers to see whats there.

Alec: she has a rummage

F: its awfy unsettling when it happens

J: you should leave your drawers out, you should tell her to piss off

F: you should buzz the buzzer and the night staff will come

B: I tried to buzz, but couldn't find it.

F: she came into Edith's room this morning and she just told her that she was in the wrong room.

M: and when she came into my room, it was terrible, she just screamed, screamed

A: 'cos she's not altogether stupid, but sometimes is quite confused.

This excerpt of interaction illustrates that the older residents with dementia were able to work together to build an account of a traumatic event in the home despite numerous confusions. Some of the mistakes the residents made were addressed explicitly, for example, the confusion between Mary Peters and Mary Mason, and others were passed over. For example, Beatrice's assertion that she had gone to find Alec in the middle of the night. Therefore, not only was

Beatrice's account given credence by the other residents, despite her confusion and mistakes, they actively supported her to construct a meaningful account of the night events. Furthermore this act of developing a shared account served to strengthen the social relationships between the residents present who worked together to position themselves as all victims or potential victims of Mary Mason's strange acts. This example shows that having dementia in Elm View was not necessarily any more problematic than being old and frail and living in the home. Furthermore, these findings highlight the importance of others in supporting the communication of older people with dementia (Crisp, 1995; Killick and Allan, 2001; Kitwood, 1997; Sabat, 2001). However, by demonstrating that other people with dementia may fulfil this role, they move emphasis away from the need for carers to support the communication of people with dementia towards thinking about how residents with and without dementia might work together to support each other.

The picture portrayed of having dementia has so far been relatively positive. However, not all residents with dementia were always able to overcome their communication problems and many of the residents were at times silenced by their cognitive impairment. For example, reviewing a video taken in the craft room showed that Mary Peters was consistently outpaced by the conversation and her efforts to contribute were ignored as they came too late or too hesitantly. However, even this example highlighted the importance of context. Towards the end of the morning, when the music had stopped and the other residents had become tired and less vocal Mary Peters, was able to find space

to share a story about her mother with the other residents. Therefore it is clear that having dementia did threaten the projects of the residents of preserving self-identity, self-determinacy and social relationships. With some support, however, all of the residents with dementia were able to resist these threats and assert a positive self-identity, maintain social relationships with others and preserve some determinacy through their communication.

6.3.2 Living with people with dementia

Dementia was something that all the residents in Elm view were forced to face and make meaningful. Although only half the residents had dementia themselves, all the residents shared the experience of living with someone with dementia and it was this, as opposed to having dementia itself, that particularly challenged the projects of the residents of preserving and creating self-identity, self-determinacy and social relationships.

Although none of the residents in Elm View explicitly acknowledged their own dementia, they were quick to identify it in others, such as Mary. The residents that were most clearly identified by the rest of the residents group as having dementia were those who experienced the most dislocation and disorientation or who refused to conform to a pattern of behaviour in the home deemed acceptable by the other residents. Residents who tried to leave the home, dressed inappropriately, slept excessively during the day, spoke as if their mother was still alive, or wandered into other residents rooms were all marked out as having dementia. However, despite these residents being clearly marked

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out as having dementia, this term was never used to describe them or explain their behaviour. Instead, residents would respond to residents identified as having dementia, or their behaviours, in a range of ways that clearly differentiated them as 'other'.

A key way of 'othering' the residents labelled as having dementia was to construct them as objects of pity. For example, Mary Peters explained Ella's behaviour of hovering by the door saying 'you see she's waiting as she thinks her sister is round the corner, poor soul. It's her age.' Whilst Maria commented that she prayed for Elsie as she was not happy and confused. More commonly, however, residents were treated with suspicion as the following excerpt from the field notes shows.

> A group of residents are sitting in the conservatory enjoying the sun. Elsie who is sitting by the door gets up to go for a walk, a few of the other residents tell her to sit down. Meanwhile Ella turns to me and says 'don't talk to her, she's a funny woman, she shouts.'

Residents felt they had to 'keep an eye on' residents who wandered, in particularly Elsie, as Beatrice said 'you never know what she'll get into next, you have to watch her all the time'. These comments reflect the very concrete threat living with some residents with dementia posed to the self-determinacy of all the residents. Many of the residents found this very challenging as the following conversation between Moira and Maria shows.

Moira and Maria are sitting in the lounge of their flat when Elsie walks in. Moira turns to Maria and says, in front of Elsie.

Moira: She's determined to get into my room, I don't know what's got into her. One night she was sound asleep in my bed with the door locked, she was there for the night, so I turfed her out. She must have been powerful in her day, she still can spell and count, if you put things to her. She sleeps all day and walks all night, knocking on peoples' doors and keeping them awake.

Maria: I was afraid and now I go and quickly close the .., in (home city) it is wonderful as they have a special place where they go, so there is no mixing with anyone as it is dangerous. You have to pay more, as I think it is very bad for the healthy people who are there. I think the families should change them to the other place, and not here.

The extent to which Maria felt threatened by Elsie's wandering in particular is encapsulated in her use of the word dangerous. Elsie's wandering threatened Maria's projects of preserving self-identity and self-determinacy in many ways. By wandering into Maria's private space, Elsie threatened her self-determinacy and ability to make the best of being in the home by carving out her own sacrosanct space within it. Furthermore, Elsie's refusal to make the best of being in the home, and obvious distress at being there, challenged the response that the other residents had developed to negotiate the impact of being old, frail and in a home on their self-identity. Finally, living with people

who were obviously confused and disorientated brought home to the other residents what kind of a place they were in and challenged them to face the reality that what had happened to Elsie could happen to them. As Jean said after I asked her if Ella talking about her mother bothered her, 'No, its something to laugh about. I do wonder how people get into that state, it makes you think, it could have been me'.

Living with others with dementia was problematic for the residents as it made them face their fear of dementia. Thus residents dealt with the fear associated with dementia not in relation to themselves, but through others. The findings clearly show that dementia was stigmatised in the home, however that the story is more complicated than the account of stigma presented by Goffman (1961). The residents did not acknowledge they had dementia and therefore did not directly accept the stigma of dementia as applied to them. However, they did acknowledge the courtesy stigma experienced through living with others with dementia and worked to counter that through their interactions in the home. Thus, the findings highlight the agency of the residents and their ability to resist the threats to their projects caused by living with people with dementia. However, the findings also highlight how threatening this dynamic was for residents such as Elsie who was regularly the subject of interactions such as the one carried out in her presence between Maria and Moira. The influence of being identified as having dementia by other residents on communication is explored in the next section.

6.3.3 Being identified as having dementia

A key consequence of the efforts of the older residents to resist the threat to their projects of living with people with dementia, was the disparagement of the residents who were identified as having dementia and 'othered' through their interactions. As the examples presented over the previous pages illustrate, residents who were identified as having dementia regularly faced threats to their self-identity, self-determinacy and social relationships in their face to face interactions with others in the setting.

Residents who were identified as having dementia received regular threats to the project of preserving a positive self-identity. As in the example presented above, of Maria and Moira's conversation about Elsie, residents identified as having dementia were spoken about in disparaging ways in their presence as if they did not exist. For example, one day I was chatting with Lena and Maureen, and addressed a comment to Maureen who did not reply verbally, but just looked at me. Lena then turned to me and said:

> 'She is a lovely lady, but she doesn't talk to anyone. When I first came here I thought she didn't like me as we would sit together and she wouldn't talk to me, but now I know I was wrong to worry, she doesn't talk to anyone.' 'She listens though ' I say, feeling awkward at Lena is saying all this while Maureen sits beside her. Maureen nods at me.

The projects of the residents of preserving self-identity was also threatened in their interactions with staff who from time to time spoke to them in infantilising ways. Ella, in particular, was addressed in this demeaning way by the staff. On one occasion she was sitting in the craft group with a doll and two carers came in and teased her. 'Hey Ella, look at you the baby sitter, is that your bairn?' On another occasion, as Ella tried to leave the home, a member of staff asked her to 'take your bike out the back to the bike sheds' (referring to her zimmer) to encourage her to stay in the home. It is interesting to note that this was one form of communication that I never observed residents to use with each other.

A key way in which residents who were identified as having dementia had their project of preserving self-determinacy threatened, was by being spoken about but not addressed directly. Thus in this interaction, although Beatrice addresses Ella directly, she also carries out a conversation about Ella's day with Jean, instead of giving Ella the chance herself to talk about her outing.

> In the craft room, Beatrice turns to Ella and says
> B: How did you enjoy your day yesterday Ella?
> E: pardon
> B: did you enjoy your day yesterday?
> E: yes
> Beatrice: lovely
> J: Where was she? (to Beatrice)
> B: Up the town

J: herself?

B: no with the others (then to Ella), The bus driver was nice wasn't he?

At other times, however, residents threatened the self-determinacy of each other by directly challenging their competence or judgement, as shown by the interaction between Jean, Ella and Nan, discussed in chapter five. The 'othering' of the residents identified as having dementia also threatened their projects of preserving social relationships.

These findings show that the residents who were identified as having dementia were subject to the depersonalising malignant social psychology outlined by Kitwood, even in the context of a care environment that provided person centred care. Residents were sometimes able to ignore these disparagements, however, more often the threats influenced their communication in two key ways. Most commonly, the residents accepted the meanings and were silenced in the disparaging interactions, unable to resist the meanings and therefore as in the examples shown in this chapter, left silent. Occasionally, however, as the example presented in chapter five showed, the residents were able to resist the threats and act in ways to protect their projects of preserving self-identity, self determinacy and social relationships. Resisting, however, was a dangerous strategy, leaving the residents open to more disparagement. Whether a resident resisted or was silenced, it was clear from my viewpoint as an observer that these interactions caused the residents great discomfort. Many of Elsie and

Ella's interactions in particular, were characterised by uncertainty, and it was almost possible to see the cogs turning as they worked out how to deal with the latest threat. This led the resident to take their frustrations out on the other residents, as the following example illustrates.

Ella, Nan, Elsie and Senga, a resident with dementia who spends most of her time in her room are eating supper at the same table. The mood at the table has turned from being quite civil and cooperative to awkward. Ella had poured tea over her scrambled eggs, which Senga told her was disgusting. Ella had said it was fine and started to eat them, when the carer whipped the plate away and replaced it with another. When Ella did the same to the second plate, the carer took that away too, leaving Ella just eating bread and butter, very disgruntled at being told what to do. Elsie then turns to her and says:

Elsie: you and I seem to know each other

Ella: (looking straight ahead) I don't know what you're talking about

Elsie: where are you from?

Ella: Petersfield (still looking ahead)

Elsie: where in Petersfield

Ella: Petersfield and (names another suburb where she had also lived)

Elsie: ah that explains it (nodding more satisfied)

Ella: do you get the picture now? (crossly)

Then Ella turns to Nan and points to a napkin

Ella: put that in your bag

Nan turns away and says nothing

Ella: for me, go on it's clean (pleadingly)

Nan looks away again and then just gets up and leaves the table.

After an awkward pause Elsie turns to Ella and says

Elsie: well I'll go and comb my hair and wash my face

Ella: aye, you'll get it in there, pointing towards rooms

Elsie: aye, you get tired don't you

Ella: aye, but you have to take it

Elsie: oh dear well, I get quite tired, but we'd better clear the table.

As Elsie leaves the table Ella mouths to me that she's not well and that she's always going into the rooms and that you have to watch her all the time. She then tells me that she is desperate to get out of here and away to her mother.

In this interaction, Nan, Senga and the carer all acted in ways that threatened Ella's projects of preserving self-identity and self-determinacy, by highlighting her confusion over the scrambled eggs and refusing to comply with her request to take the napkin. Ella responded to these threats by in turn threatening Elsie, and in seeking to distance herself from Elsie's confusion through her comment to me. Thus residents who were threatened by dementia, dealt with this by disparaging others identified as having dementia and residents identified as having dementia in turn disparaged other people with dementia. This led to what I am terming a hierarchy of confusion in the home, with every resident working through their interactions to present themselves as less confused than those around them. These findings echo those of Hazan (1994), who observed

a similar phenomenon in an Israeli nursing home, with all residents working to portray themselves as most independent.

The consequence of the presence of the hierarchy of confusion in the home was that many of the interactions I observed in the home were characterised by uncertainty and insecurity. As will already be apparent from the excerpts of data presented in this chapter, there was a lot of conflict between residents. As often as residents worked together to overcome the communication difficulties they experienced, they worked against each other, threatening the projects of each other and silencing each other. This meant that the residents' communication was not only influenced by the meanings they made of living with people with dementia themselves, but also by the response of other residents to the impact of those meanings on their projects.

6.4 Conclusions

This chapter has examined the meanings the older residents made of being old, having dementia and living in a care home. Analysis of the findings revealed that all these aspects of experience influenced the communication of the older residents. The meanings they made of being old, living in a care home and dementia, threatened their projects of preserving self-identity, self-determinacy and social relationships. This forced the residents to act through their communication to try to address these threats. However, it is important to note that these different aspects of the experience of the residents threatened their projects in different ways. Residents were able to resist the threat to their self-

identity posed by ageing by working alone and together to highlight the wisdom and experience that being old afforded them. Similarly, residents were able to resist, or at least mediate, the threat to their self-identity posed by the meanings they made of having dementia by refusing to acknowledge their dementia and by constructing it as a normal part of frailty. The meanings the residents made of being frail and living in a home, however, proved more difficult to negotiate, silencing the residents.

Thus this chapter explores the meanings the older residents made of themselves in relation to the societal facet of context. The meanings they made of their experiences of being old, frail and living in a home were shaped by societal discourses of ageing, dementia and institutionalisation that they had been exposed to over the course of a life time. The ways in which the residents viewed themselves were influenced by how they thought society viewed them and the residents made sense of their own experiences with reference to the 'generalised other'. Furthermore the meanings the older residents made of themselves in relation to society were also reproduced in their interactions with others in their streams of action. Residents responded to threats in the societal facet of context by seeking to distance themselves from those meanings. In the case of the threat posed by dementia, and living with people with dementia, this led them to 'other' people who were identified as having dementia. In this way, residents responded to the ways in which their projects were threatened in their interactions with the societal facet of context by threatening others, leading to a hierarchy of confusion in the home. This meant that some people with dementia

were threatened not only in their interactions in the societal facet of context, but also in their interactions with others. It is important to reiterate, however, that the residents who were identified as having dementia were not necessarily those with the most advanced dementia, but were the residents who challenged the efforts of other residents to integrate life in the home with a positive self-identity.

The chapter also identified a number of ways in which living in a care home, being old and having dementia influenced the communication of the older residents materially. Living in a care home influenced whom the residents encountered in their streams of action and therefore those with whom they were able to interact. In particular, the residents had few opportunities to interact with people outside of the home. Furthermore, as the dementia literature highlights, the communication of the older residents was influenced by the cognitive impairments they experienced. Observation of the interactions of the older residents revealed that they experienced a number of problems communicating. However, the residents, in conjunction with others, were often able to overcome these problems and successfully negotiate meaningful interactions, as the many excerpts of data presented in this chapter show. The importance of the others in the interaction to the success of the interaction was, however, highlighted.

This chapter makes two key contributions to understanding the communication of older people with dementia living in residential care. First, the chapter

examines the communication of the older residents in relation to the meanings that they made of the societal facet of the context in which they lived. This highlighted how the awareness amongst the older residents of negative discourses around ageing, dementia and institutionalisation and the marginalisation and exclusion of older people with dementia, coloured their interactions. Furthermore, conceptualising communication in relation to threats and supports to the projects of the residents provides a frame to understand how processes of exclusion and marginalisation were reproduced in the interactions of the residents with others in the home and how this influenced their communication in profound ways. Thus this chapter adds an important dimension to the understanding of the communication of older people with dementia in residential care.

Secondly, by examining interactions between residents with dementia themselves, as opposed to their interactions with carers, this chapter makes a key contribution to understanding communication and dementia. As review of the literature in chapter two highlighted, to date, the communication of people with dementia has been explored almost exclusively in the context of interactions with carers or researchers. However, this chapter highlights what an important role other residents play in shaping interactions and influencing communication. Thus, even though the staff in the home generally provided very good person centred care, residents, through their interactions with each other perpetuated a malignant social psychology in the home. These findings

highlight the need for person centred approaches to care to find ways to support positive interactions between residents instead of relying on staff alone.

The issues raised here and their implications for policy and practice as well as understanding of communication and dementia are explored in more detail in the concluding chapter of the thesis. First, however, chapter seven examines the ways in which the communication of the older residents was influenced by the specific institutional context that was Elm View.

Chapter 7

The influence of the Institutional context of Elm View on the communication of the older residents with dementia

7.0 Overview

The findings presented in chapter six revealed the diverse ways in which being old, having dementia and living in a care home influenced the communication of the older residents. In this chapter, the ways in which the specific institutional context of Elm View influenced the communication of the older residents with dementia is explored.

The research reviewed in chapter two highlighted the importance of the institutional context in supporting or threatening the communication of older people with dementia. This research highlighted how the communication of older people with dementia was threatened by depersonalising care environments (Athlin and Norberg, 1989; Kitwood and Bredin, 1992; Kitwood, 1997), and revealed the ways in which the pressures of providing care to large groups of people meant that the individual needs were subsumed within total institutions (Goffman, 1961; Patterni, 2000). As the review of the policy and practice context in chapter one highlighted, there is, however, much consensus as to how care can and should be provided to support the communication of older people with dementia. Many of these recommendations were put into

practice in Elm View, which, as has already been noted, was recognised for providing good quality care.

This chapter examines the encounters the residents had with the institutional context of Elm View. Findings are presented on the meanings the older residents made of the institutional context, how those meanings impacted on their projects and how they responded to those meanings through their communication. Furthermore, the chapter examines the ways in which the communication of the older residents was shaped by the care context in more material ways, in particular, through determining the kinds of encounters the residents had in their streams of action. Thus, this chapter explores how the residents made meaningful and responded to, a care context that adheres to current conceptions of best practice, and how this care context shaped the communication of the older residents. The analysis presented in this chapter focuses on two key aspects of the context, the spaces in which the residents lived and the caring regime that determined the way their care and lives were organised.

In the following section the influence of the spaces in Elm View on the communication of the older residents is considered. The ways in which their communication was shaped by the caring regime is considered in section 7.2.

7.1 Spaces in Elm View

The importance of space in determining the lives of older people with dementia living in residential care has been widely noted. Theoretical research on social interaction has shown that people make meaning of the space around them and that these spaces shape their interactions (Harris and Lipman, 1980; Laws, 1997). Empirical research on the experiences of people in institutional care revealed the presence of two different kinds of spaces in residential care, private spaces that the older residents have ownership of, and public spaces that no one has ownership of. The England and Wales and Scotland Care Standards for care homes for older people outline the right of all residents to private space and shared space for communal activities (Department of Health, 2001; Scottish Executive, 2002). Furthermore, best practice publications highlight the role of space in homes in supporting the self-identity of the residents (CPA, 1996) and in supporting their choice, determinacy and independence (Marshall, 1997; Peace et al, 1997). Specifically these guidelines highlight the importance of the residential space being fully accessible, including to outside areas (CPA, 1996), homely (Marshall, 1997) and being well signed to promote orientation (Marshall, 1997). Furthermore, these guidelines highlight the benefits of living in small groups towards promoting a sense of shared identity for the residents.

As already described in section 4.2.1, the residents in Elm View had their own rooms which were grouped together in communal flats. This meant that residents had access to three distinct kinds of space in the home. Private

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space, which was their own rooms; communal space, the communal living and bathing areas that they shared with their five flatmates and public space, all the other areas in the home. Over the following sections the ways in which each of these three kinds of space shaped the communication of the older residents is examined.

7.1.1 Private space

The only private space the older residents had in Elm View was their single room, which was furnished with a bed, sink, and wardrobe reflecting the denoted function of the room, for sleeping and engaging in personal care. Beyond these constraints, however, residents were free to furnish and spend their leisure time in their rooms as they pleased. A Better Home Life (CPA, 1996) highlights the importance of the rooms of the residents to their self-identity. In Elm View, residents were encouraged to bring in personal items such as photographs and pictures, and many residents had their own furniture in their rooms. Having the names of the residents, and sometimes pictures, on the doors to the rooms also reinforced the ownership of the residents of the space. In these ways, the institution encouraged the residents to view this space as their own and sought to support the projects of the residents of preserving self-identity and self-determinacy.

Analysis of the findings revealed that the residents made meaningful and responded to their private space in a range of ways. For some residents their rooms were the main location for their leisure activities and were where they

spent most of their time. For example, John, a resident without dementia had a piano in his room and would spend hours playing it. Other residents however, used their rooms as more of a base. These residents kept their belongings and signifiers of their ties to the outside world in their rooms, but spent most of their time in the communal or public spaces of the home. Having visitors in one's room held great significance for some residents, who would occasionally invite me into their rooms for a chat. On these occasions the conversation was often of a personal nature, about their families and life before coming to the home. For example I wrote the following notes after a conversation with Nan in her room

> Nan spoke to me at length about her time working at the (historic building), and talked about her childhood as one of 13 growing up in (name of street). She spoke emotionally of her mother dying when she was young and the loss of her brothers during the war. A picture of the ships they had sailed on was on her wall which she showed me whilst telling the story.

For most of the residents, their private space in the home was important in supporting their projects of self-identity and self-determinacy, creating a space for them to pursue leisure activities and for their significant belongings. This space was closely guarded and many residents locked their doors when they were not there. Others in the setting, including staff and visitors to the home, respected the ownership of the residents and their right to control this space, and would always knock before entering the room of a resident. Breaches of

this respect, for example when a resident with dementia wandered into the room of another resident, caused great upset amongst the residents, as the excerpt of video recorded conversation in the craft room about Mary Mason's wandering, presented in chapter six, showed. During this conversation not only was the wandering behaviour of Mary condemned by all the residents and the staff member present, but wandering into rooms was generally identified as a problem to which residents and staff had developed solutions over time, for example locking the room and using the buzzer. These findings support the research of Gubrium (1975) in an institutional care setting which also found how upset residents became when others wandered into their private space.

Despite the vital role of the private space of the residents in supporting their projects of self-determinacy and self-identity, residents were unable to completely control this space. The care standards and guidelines reviewed in chapter one highlighted the importance of privacy to the residents and assured residents that staff, other residents and visitors, would knock before entering their room (CPA, 1996; D of H, 2001; Scottish Executive, 2002). However the requirement to knock did not stop staff members needing to go in and out of their rooms countless times a day to clean, change sheets and in the case of some residents, to help them dress. Furthermore, if unlocked, other residents could wander into the room at any time, threatening the self-determinacy of the resident whose room it was. Thus even in the private rooms of the residents it was impossible to forget that they were in an institutional care setting. Indeed the difficulties the residents and institution faced maintaining private space for

the residents in the setting were visibly played out on the doors to the rooms of the residents. These were identified both with the names and photos of the residents and also with a number. On several occasions I heard maintenance staff refer to rooms of the residents by number and not name, showing that when it came down to it the institutional meanings were more powerful.

7.1.2 Communal space

The second kind of space in Elm View was communal space. Small group living has been recommended as a means of supporting the development of a sense of shared identity and community between residents in the home (e.g. DHSS and Welsh Office, 1973; CPA ,1996 and Wyvern Partnership, 1979). As described in section 4.1, these recommendations had been followed in Elm View and the rooms of the residents were grouped together in flats with six residents in each. This space was decorated with floral wallpaper, books, coffee tables and ornaments and was designed to feel like home for the residents. Residents were encouraged to take control over the space and play a role in determining how it was run. Thus, through the use of communal space, the institution sought to foster the self-determinacy of the residents, support the development of relationship between residents in the flats and, by giving them a nice homely place to live, support their self-identity.

Observations in the communal spaces in the home revealed that residents made meaning of these flats in two key ways, as community spaces to be shared and territory to be defended. One resident who firmly conceptualised her

flat as community was Lizzie. Reflecting her perspective of the importance of work, Lizzie embraced the opportunities for self-determinacy provided by this space and created meaningful work for herself, making tea for 'her ladies' every morning and afternoon. This task also enabled her to maintain social relationships with her fellow residents as it provided a structure for her interactions with them. For other residents, the flat was a space for companionship, where residents would sit watching television together, making the occasional comment. As Nan commented when I referred to her flatmates, 'Flatmates? There's not anybody who's my flatmate, we're just all friends here!' Through her use of the word friend, Nan sought to normalise her relationship with her flatmates, constructing them as everyday companions as opposed to co-residents. However, this did not stop her and many of the other residents acting with consideration of others. For example, one resident who had a hearing impairment would watch her television with headphones on to avoid bothering her neighbours and John would only play his piano during the daytime.

Many of the residents, however, were unable or unwilling to acquiesce to the preferred 'top down' meaning of the communal space in the home as communal and instead responded to it as territory. For these residents, the communal nature of the space and the requirement to negotiate use with others, threatened their projects of preserving self-determinacy. Residents responded to these threats by colonising particular chairs or the television at certain times of the day. Residents also got annoyed with having to listen to each other talk

about the same things day in and day out. One resident who caused particular annoyance was Maria, who sang and chatted constantly. As Elsie and Geraldine commented:

> E: see that bletherer, she can talk for hours and hours
> G: talk the hind legs of a donkey
> E: And I never ken what she's talking about, abroad, abroad, and boyfriends, my god, my god (shaking her head)
> G: I like peace and quiet
> E: yes

Maria was aware of the annoyance she caused Elsie when she said 'that Elsie complains of my singing, but I have to put up with her coming into my room at night, it's not nice!' Thus the projects of the residents of preserving self-identity and self-determinacy were threatened in this space. However this space was also central to their projects of preserving social relationships, and interactions with others in this space were of vital importance to them. This meant that the communal space in the home was a place of conflicting meanings for the residents, who made meaning of it as both territory and community. Through their interactions in this space, they sought to negotiate the opportunities for companionship afforded by the space, but on their own terms.

The difference between residents with and without dementia also became most apparent in the communal spaces in the home, as the residents negotiated many tasks of daily living together in these spaces. The problems some

residents with dementia had with these activities became very obvious in the communal space in the home. This led to great upset for both the residents with dementia and their less cognitively impaired flatmates, and at times their interactions in this space became quite vitriolic. One resident without dementia, who got particularly annoyed with his flatmates with dementia, was Peter, and one day I recorded on video a not untypical interaction he had with April, a fellow resident with dementia.

Peter is seated in his chair when April comes up and peers at the name label on his zimmer frame in front of him.

A: Is this mine? (as she peers over him)

P: Take a fucking look, take a fucking look you cow (Peter picks up the frame and waves it violently in April's face)

A: I'll knock your head off in a minute you moaney old devil, I've got to have a look to see if it is mine. My god!

P: You know where yours is so go and get it

A: My god! I'll strangle you

P: Go on, Piss off! (then turns to the camera and half smiles looking pleased with himself, aware his outburst has been caught on film

A: (to me) is this seat free?

Exchanges such as these were common in the communal spaces of the home and reflect how stressful it was for the residents being put in a situation where they had to negotiate life with five other people from diverse backgrounds and with diverse perspectives. Mealtimes were occasions that were particularly

fraught with difficulty in these spaces. Residents worked hard through their interactions to avoid sitting with others they did not like, or who ate or behaved strangely. This problem was solved in the flats where the residents sat in the same seats everyday, demarcated by personalised napkin rings. However, in flats where residents could sit where they wanted, seating arrangements caused prolonged stress. In this way a policy that sought to promote choice and give residents control over the space actually caused them more problems. On one occasion, I observed Lizzie spend a full twenty minutes before a meal time discouraging her flat mates with more advanced dementia, in particular Elsie and Ella, from sitting at her table whilst trying to ensure that Beatrice had a place next to her. Staff often became involved in these situations and would generally act on behalf of the less impaired residents, as the excerpt of video presented in section 4.4.1 showed. In this interaction Jim, a care worker, forcibly moved Elsie from her chair to make space for a less impaired resident.

Despite all the conflict, the communal spaces in the home were a key arena for the development of relationships between residents and all the close relationships in the home occurred between residents sharing the same flat. Sharing the same flat meant that residents spent a lot of time together during the day, got to know each others' family and visitors and also spent more intimate time together in the evenings. Speaking of her relationship with Jean, Mary Peters told me.

'She's an awfy woman, but a good pal, I wouldn't know what to do without her. When my sisters come they spend more time chatting with Jean than me! It's not the same in here, but I make do. I don't know what it would be like without my pal Jean.' Mary then tells me that when she came back last night at eleven pm after a concert, Jean was waiting up for her to get home and tells me how touched she was.

Indeed the importance of these spaces to supporting relationships was highlighted when Elsie was moved to a flat downstairs which ended her friendship with Geraldine. Elsie's dementia was such that she seemed to have forgotten about Geraldine when she was not immediately present. Geraldine, although she often spoke of going down to find her friend, did not have the confidence to do so.

The communal spaces in the home had an important influence on the communication of the residents, being rich arenas of conflict and companionship. The residents made very different meanings of these spaces and it was clear that some residents were able to wield more power and determinacy than others. This meant that different residents experienced the communal spaces in the home in very different ways and while for some, many of the meanings they made of and in these spaces were supportive to their projects, for others these spaces threatened their projects of preserving self-identity, self-determinacy and social relationships.

7.1.3 Public space

The final kind of space in the home was the public space. Both the Scottish and English and Welsh Standards for care homes for older people highlight the need for public spaces in the home where residents can gather together for social and communal activities (D of H, 2001; Scottish Executive, 2002). The CPA (1996) also highlight the value of what they term a 'semi-public' space that residents can visit, giving them the sense that they have got out of the confines of their room. In Elm View, as already described in section 4.1, there were several public spaces, the key one being the Foyer, which, as it was located in the centre of the home, was full of comings and goings. Anyone entering or leaving the home passed through this space as did people passing from one flat to another. This space was designed to be the hub of the home, but also a place for surveillance of what was going on. The space was decorated with posters and photographs of the residents and therefore was where the identity of the institution was constructed. Although this was a space for residents, the institutional meanings were less determined than in the private and communal spaces and, as highlighted in chapter four, the large space was used for a range of activities.

Unsurprisingly, the residents responded to this space in many different ways. Although residents rarely needed to enter this space, other than smokers whose cigarettes were kept in the office, many chose to spend time in the public areas of the home. The behaviour of the residents in the setting reflected the different meanings they made of this space. Some residents dressed up for this

trip to the foyer, and brought handbags and coats, reflecting a view of this space as somewhere different, outside. For others it was where they smoked, found company or was the last place they would turn to when they wanted something to do. Residents often came to the public spaces of the home to get away from either the noise in their communal lounge or looking for company when their communal lounges were quiet. On sunny days, the conservatory in particular would be full of residents chatting or just sitting soaking up the sun. As Gubrium (1975) found, watching what was going on was a key activity in this space and at times residents sitting together would construct a shared commentary of the comings and goings, as the following example shows.

Jean, Ella, and Beatrice were sitting together in the foyer when one of the men who attended day care walks past and calls out goodbye to them all. However a minute later he comes back.

E: He's back

J: He's looking for a woman!

E: He's looking for someone to make love to. (To Jean) Go and make love to him.

J: He'd have to do all the work

They all chuckle and Beatrice winks at me

B: He's away

J: No he's looking for something

As the man turns and leaves finally Ella says

E: He's a straight man, he goes straight out and gets a bus

B: He's away.

Unlike communal spaces in the home, individual residents claimed no ownership over the public spaces. Residents did not colonise particular chairs and, aside from the smokers, residents did not respond to the space in a routinised way. In this way Elm View was very different from Murray Manor, where Gubrium (1975) did his fieldwork, and observed the residents to contest space fiercely. The unroutinised, uncolonised nature of this space meant that the residents had little control over the space and could not be sure when they visited, whom, or what, they would find. In particular, in entering this space, the residents had to balance the opportunity that they would find enjoyable company or activity with the risk that they would have to interact with residents they did not like. In this way, the public space was much like the communal spaces in the home and could be both supportive and threatening to the projects of the residents. The residents developed a range of different strategies to help negotiate their interactions in and with this space and the risks associated with them.

Moira would always come to the foyer with a magazine or paper that she would study carefully when spoken to by residents she did not want to talk to. John, who spent a lot of time in the public spaces of the home, as he was unable to smoke in his own flat, simply got up and moved if he did not want to engage with residents around him. This was a strategy that Ella frequently engaged in, as evidenced by the interaction presented in chapter 5.0. Both these behaviours which would be seen as rude in other settings were completely accepted in the

public spaces of the home. On several occasions I observed the residents use the furniture to encourage or discourage other residents from joining them. During one interaction, Nan pulled round a chair and arranged a cushion as Ella approached, encouraging her to sit down, and Jean moved the coffee table to let her through with her zimmer. A few minutes later, however, she moved it back to discourage Mary Mason from joining them, telling her 'you can't get round this way you'll have to go over there'. This did not mean that public spaces of the home were free from confrontation, as Mary Peters commented one day about Ella and Jean 'they two fight like two girls in the playground', but merely that there was both the physical and social space for residents to disengage or leave when they got annoyed with each other. Thus some residents who were oppressed and bullied in the communal spaces of their flats had far more determinacy in the public space as a different set of conventions applied. For example, a member of staff tried to encourage Ella to sit and chat with Alec, however, when Ella realised who he was, she said, 'oh no I can't sit here, the doctor has said I'm not to'. Therefore, in this space, Ella was politely able to resist the intervention of the care workers and avoid the unwanted company without creating a scene.

The one public space in the home where some residents did feel a sense of ownership was the craft room. The craft room was upstairs and could seat up to fourteen residents round a table. Although open all the time, the room was only ever used for the craft group that was run four mornings a week by the activity leader, Fiona. A core group of residents attended this group most days and

other residents rarely entered the room. The significance of the room to those who used it was clear. When asked what they liked about the room the residents commented on the light, warmth, cosiness and friendly atmosphere. Residents tended to sit in the same chairs every time the group met and the importance of this to Jean was apparent when she said 'I wouldn't like to sit facing in!' Ownership of the room was reinforced by the displays of the art and craftwork of the residents around the room, and each regular attendee had a shelf where their ongoing projects were kept. Thus, the room and group supported all the projects of the residents of preserving their self-determinacy, social relationships and self-identity.

The craft room was the only space in the home that was not purpose built. The room had been designed as a meeting room, but had been taken over as a craft room when the home obtained extra resources to pay for an activity leader. As a result, the room bore no top down meanings. Instead the regular users of the room had actively endowed the room with their own meanings through their interactions and activities in it. The symbolic meanings the residents made of the craft room included as being a place for intimacy, activity, support, reminiscence and friendship. However, the flip side of the ownership that the residents felt of the space was that they viewed it as their territory and they were unwilling to let others join in. For example, when I walked into the craft room with Elsie, Heather, a resident without dementia told Elsie as she was about to sit down 'you can't sit there, that's Rene's chair' even though Rene had gone to the doctors and was not attending the group that day.

Analysis of the findings highlights the importance of the public spaces in the home to supporting the projects of the older residents, in particular those who were dominated and threatened in the interactions they had in the communal spaces in the home. Residents moved around this space very freely, seeking out and avoiding interaction as they chose. Thus, although the care regime imbued this space with far fewer opportunities for self-determinacy than the communal spaces in the home, in practice the public spaces in the home were vital to supporting the self-determinacy of the older residents.

7.1.4 Reflections

Elm View consisted of three key kinds of space, all of which had been carefully designed to support the projects of the older residents of preserving self-identity, self-determinacy and social relationships. Examination of the communication of the older residents with dementia in relation to the spaces in Elm View revealed that the residents interacted with the space and made it meaningful. However the meanings the residents made of these spaces did not always correspond with those intended by the institution. Different residents made meaning of and responded to these spaces in a range of ways. Just as some institutional meanings were more powerful than others, some residents held more power in these spaces. This meant that spaces that were designed to promote the development of a sense of community and shared identity in the home, were the locations of some very threatening interactions. Furthermore,

the spaces in the home influenced the communication of the older residents by determining the kinds of encounters the residents had in their stream of action.

In the following section the ways in which the residents made meaning of and responded to the care regime are examined in detail. In particular the meanings they made of the provision of personal care, staff in the home, and the opportunities for activities and involvement in home life are examined in detail.

7.2 Care regime

The importance of care philosophy and care regime in determining the kinds of experiences and interactions older people with dementia have in care settings forms the central tenet of person centred care (Kitwood, 1997). The work of Kitwood highlighted that depersonalising care regimes threatened the personhood of older people with dementia and also their ability to communicate. Furthermore the England and Wales and Scottish Care Standards highlight the importance of care regime in supporting the communication of older residents (Department of Health, 2001; Scottish Executive, 2002). In particular, both sets of Standards assure residents that they will have opportunities to engage in social activities, and communicate with other residents, they will be consulted about their care and the service provided to them and they will be supported to continue to engage in life in the community and to keep in touch with family and friends. In this section, the influence of the care regime on the communication of the older residents is examined. Specifically, the meanings they made of four aspects of the care regime are explored and the ways in which the regime

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influenced communication by shaping and providing opportunities for interaction are described.

As already highlighted, the care provided in Elm View was of a high standard and the staff and management worked to ensure that the communication and quality of life of the residents was supported by the regime. However, as with the space in the home, the residents made their own meanings of the regime in the home and it was these meanings, as opposed to those intended by the institution that shaped their communication. In the following sections, the relationship between three aspects of the regime and the communication of the older residents are considered. These are: the provision of care; the staff and opportunities for involvement in activities and home life.

7.2.1 Provision of personal care

The home was responsible for the personal care of the residents. This involved providing meals and shelter for all residents and support with washing and dressing for some. The literature on institutionalisation highlighted how individuals have been subsumed by institutional care settings, subjectified and responded to as objects of care, which threatened their self-identity and self-determinacy (e.g. Goffman, 1961;Patternitti, 2000). Indeed, much of the literature on life in residential care has focused on the oppressive, restrictive and surveillance orientated nature of the place. In her PhD thesis, McColgan (2001) comments that as a researcher visiting the home, staff monitored her movements, reflecting the extent to which the regimes in the home were

established to monitor the residents. However, the Scottish Care Standards highlight the need for care regimes to respect the rights and dignity of the residents, giving them choice and valuing them as individuals (Scottish Executive, 2002). Elm View embraced these values and sought to bolster the self-identity, social relationships and self-determinacy of the residents through the provision of care in the home.

The regime at Elm View was relatively flexible in terms of the day-to-day experiences of the residents in the setting and in this way sought to preserve the self-determinacy of the residents in the home. Residents got up when they wanted, and it was not uncommon to see residents wandering around in their dressing gowns at any time of the day. Many of the spaces in the home were relatively unobserved and on a couple of occasions I spent a two hour observation period in the home without speaking to a single member of staff. This experience was reflected by Lizzie's observation 'I like it here, they leave you alone, you can do what you like and they still give you your meals'. Residents were given space to create their own regimes, for example Leslie went to the local pub twice a week for a lunch time half-pint. However, only the least impaired residents were able to take advantage of the opportunity provided to engage in these kinds of activities.

Although the regime was designed to be very flexible, in practice residents who took advantage of this flexibility laid themselves open to disparagement and criticism from other residents. For example, Lizzie reported to me with a look of

disbelief that Elsie 'stays in her room all morning and wants her cup of tea in bed'. Similarly, Jean commented when April came into their communal lounge one afternoon 'here's April, in her dressing gown, she was wandering about all day in just her dressing gown and a pair of shoes last week.' It seemed that the structure provided by the care regime in the home was important to the self-identity of many of the residents as it helped preserve the illusion that life in the home was no different from normal. Therefore, residents who took advantage of the flexibility in the home by getting up late challenged this illusion and therefore the projects of their fellow residents.

Many residents reported enjoying life in the home and praised the good care they received. Beatrice and Lizzie both commented that the home was good and clean, whilst Nan told me that she liked it in the home as it was safe. Beatrice thought they were lucky to be here and would often tell other residents about her sister in Canada who told her that they wanted homes like Elm View there, but could not afford to provide them. Rene, when I chatted to her sitting in the conservatory in the sun one day, told me that 'It's a nice place really, there is lots of company here, and its good as the other residents are old but not too old', adding that it was much better than the last place she had lived. Lizzie echoed this sentiment, 'there are lots of nice old ladies for company, and men too'. The features of the home the residents liked reflected their perspectives on life and what it was they particularly valued. Thus as we have already heard, for Nan, being safe was of primary importance, whereas for Beatrice, what was important was that she felt they were lucky to be there.

Despite the person centred care philosophy in Elm View and the flexible daily routine, Elm View was not able to meet the needs of all the residents all of the time, and as a result, many of the residents were unhappy in the setting. The loss of control they experienced over the small aspects of their daily lives, such as never knowing when their underwear would return from the laundry and what they would have to eat at night, challenged their projects of preserving self-determinacy. Furthermore, many of the residents were very resigned to their situation and felt that there was nothing that they could do to change it. This was reflected in the ways in which they spoke about their situation, as the following conversation between Rene and Maria illustrates.

> Rene and Maria are sitting watching television when I come in to chat to them. We start talking about life in the home and Rene says:
> Rene: There is nothing to do in here, we just sit cooped up in here. It would be alright if I could go outside, but I would need someone to push me.
> Maria: But I could push you! In the summer we go out together, to the garden, and we can push each other
> R: No, no, I'm too heavy, and where would we go?

Jennifer echoed these sentiments saying 'It's so quiet in here, we get good food, but there is nothing much to do.... I can't do much now, you can't in here'. Thus, many of the residents clearly made meaning of the regime in the home as being a place with little space for their self-determinacy. Maria was more explicit

with her criticism of the home saying: 'When I came here I was promised three trips a week and lots of activities, but they never materialise, so I mostly sit'. When I asked her if she attended the craft room, which was the main activity provided by the home she retorted, 'No I no like that, it's not like the kinds of classes I used to do'. Thus, although the home sought to provide person centred care it was unable to meet the needs of the diverse range of residents in it's care, and therefore failed to provide for them the quality of care they had hoped for.

One defining perspective that some of the residents shared which was particularly problematic in the home was that of being a smoker or a drinker. The use of cigarettes and alcohol was monitored in the home and residents had to go to the office to access their own cigarettes or alcohol. This meant that the smokers, in particular, spent lots of time hovering by the office door waiting for someone to come by to give them a cigarette. As John, a resident without dementia who smoked heavily said, 'you have to take your opportunities while you can'. Smoking was only allowed in the foyer and the conservatory of the home and therefore became a very public activity in the home. Consumption of alcohol could be done more privately but was also regulated. Jean, for whom alcohol played an important part of life, found this really difficult, especially being unable to get a sherry for what she termed her 'boozing pals' when they came to visit. When staff remembered, she was given a glass of sherry at 7pm and sometimes after lunch, however, from time to time her friends would bring sherry in for her in an Iron Bru bottle that she kept in the bag on her zimmer

frame. In this way, with the help of her friends, Jean was able to resist the challenge that the intolerance of the regime to alcohol posed to her projects of preserving self-identity, self-determinacy and social relationships.

7.2.2 The staff

The literature reviewed in chapter two highlighted the emphasis traditionally placed on the role of staff in supporting communication of older people with dementia in residential care. This literature highlighted how, through the therapeutic use of the self of the carer, they could facilitate interaction with residents with even advanced dementia (e.g. Haggstom et al, 1998). The staff in Elm View were generally very good, they were well trained and the low staff turnover enabled many staff members to establish good relationships with the residents in the home. Analysis of the data, however, revealed that the residents made a range of meanings of the staff members and the work that they carried out and it was this, as much as their interactions with the staff, that influenced the communication of the older residents.

A large body of staff worked at Elm View, looking after the forty residents and the building they lived in. Elm View operated a Key Worker system, and each resident had one member of care staff to go to for any extra help they needed. Given the responsive nature of the role, key worker tasks varied greatly from resident to resident. For many residents their key workers were an important link to the outside world. Key workers went shopping for the residents, for items such as sweets, toiletries, videos and quiz books, generally on their way in and

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out of work. For example, a male resident, Stan told me excitedly that it was his birthday next week, and Lisa his key worker was going to get him food for a party in his room. For some residents, the key worker played an important role in helping them keep in touch with their families, by buying cards and reminding them about family birthdays and getting them ready for visits and trips out. However a lot of key worker time was spent doing the extra things required to maintain the physical appearance of the residents, such as mending clothes, helping buy new clothes, arranging hairdresser appointments and more intimate tasks such as painting the nails of the female residents. In these ways the key workers supported all three projects of the older residents.

Within Elm View there was a range of different kinds of relationships between care staff and residents and as a result, different care staff had very different meanings for each resident. These meanings would change over time depending on the needs of the resident at that time. The meanings also reflected the value the resident placed on the work being done by the staff and reflected their feelings of being in care.

Lizzie always referred to the care staff as 'workers' and expressed her admiration for the long hours they worked. Worker was an identity she also claimed for herself, demonstrated by the work she did making all her flatmates a cup of tea morning and afternoon. The good care the staff gave was attributed to their professionalism and she often praised their hard work. In contrast, for Beatrice, her flatmate, the care staff were more like friends. Although she knew

that the staff were paid, she viewed their hard work as a reflection of their empathy with and fondness for the older residents and herself. Indeed, for Beatrice, the care work done seemed of very secondary importance to the friendship and companionship provided by the staff. Beatrice reciprocated this friendship and care by doing things for the staff, she knitted items for her key workers in the craft group and even tried match-making two of the single, male members of staff with me.

Beatrice was not the only resident to relate to the care staff as friends. In particular Fiona, the activities co-ordinator, was a friend to many of the residents, and they would often comment on what a good woman she was in their chats with me. During the craft group Fiona would talk with the residents about their problems and empathise with their experiences, as the conversation regarding Mary entering the rooms of the other residents showed. Other staff also spoke with residents about their friends, family and experiences in and outside the home. They all made efforts to reinforce the positive self-identities of the residents, and in particular, staff commented on the physical appearance of the residents. Reed - Danahay (2001), however, suggests that care staff tend to comment on the physical appearance of the residents, as it is a concrete symbol of the good care they themselves are providing. The perception of the residents of staff as 'helpful friend' was also fostered by the institution itself. None of the staff wore uniforms, though some chose to wear overalls over their own clothes, and their title 'social care worker' was a reflection of the important social aspect of their work.

Most of the residents had a positive relationship with many of the care staff, and this was reflected in my observations. However, not all residents had such positive relationships with all the staff members and not all interactions between staff and residents were supportive of the projects of the residents. At times, staff members were observed to interact with older residents, in particular those with dementia, in demeaning ways. Staff members spoke to some residents in an infantilising way, as the example of the staff member teasing Ella about her 'bairns' presented in section 6.3.3 illustrated. At other times, staff would scold the residents and tell them off for acting in ways that caused more work or that might lead to harm. For example, Elsie was firmly told by a member of staff 'You can't leave now, you'll not come back'. In these ways, the staff members threatened the self-identity and self-determinacy of the older residents who were silenced, unable to respond to comments from people with such power in the home.

Some residents seemed to be on the receiving end of far more of these kinds of interactions than others. These residents felt the 'gaze' of the staff keenly. On one occasion I asked Peter, who had been complaining that the chairs in the conservatory were uncomfortable, why he didn't take a cushion out. He replied bitterly, 'they'd (meaning the staff) just ask me where I was going with it'. When I asked him if he had been prevented from moving furniture before he replied 'No, but they're bound to stop me'. This reply reflected Peter's view of the staff, at that time at least as controlling and constraining. Another resident who was

wary of the staff was Stan. During a visit to the home, I walked into the lounge of the flat where Stan lived and saw him sitting next to the coffee table with a cup rolling on the floor beside him. Before I had a chance to even say hello he told me anxiously 'I didn't do it, she (a cleaner) knocked it over with the hoover, I can't pick it up.' This nervous, defensive response suggested that he anticipated getting blamed for the event, even if he was not responsible and it was only when I cleared up the mess that he could relax. Again, neither of these residents were able to resist the impact of the meanings they made of the staff as disciplinarians and controlling on their projects of preserving self-identity and self-determinacy.

The relationships of the residents with staff in Elm View were, on the whole, far more positive than those reported in other ethnographic accounts of life in institutional care homes for older people (Gubrium, 1975; McColgan, 2001). Although the staff ratio in the home was such that the residents spent large chunks of the day never seeing a member of staff, many of the members of staff actively fostered relationships with residents and sought to support their positive self-identity. However, a few residents in the home had less positive relationships with and interactions with the staff in the home. These were often the residents who were most threatened in their interactions with the other residents, or who had been most marginalised outside the home. In these ways, processes of exclusion and marginalisation occurring in the societal facet of context were reproduced in the interactions of the residents in the stream of action and in the institutional context of Elm View.

The findings presented here highlight the power the staff had to influence the communication of the older residents in both positive and negative ways. Some residents, such as Beatrice, visibly blossomed in the caring attentions of the staff, whilst the actions of the staff silenced other residents, such as Stan. In the context of a generally good caring environment, however, the staff did not constitute a particularly important influence on the communication of the older residents. The residents rarely saw staff and instead spent most of their time in interaction with other residents, who, as found in section 6.3, had profound supportive and threatening influences on each other's projects and communication.

7.2.3 Activities and opportunities for involvement in home life

The literature reviewed in chapter two highlighted the value of social activities in supporting the communication of older people with dementia (e.g. Crichton, 1997; Killick and Allan, 2001). Furthermore the Care Standards and guidelines presented in chapter one highlighted the importance of providing opportunities for the older residents to be involved in life in the home (CPA, 1996; D of H, 2001; Scottish Executive, 2002). The care regime in Elm View had embraced these recommendations and there was a programme of social activities for the residents as well as opportunities for the residents to be involved in the running of the home. In these ways, the home sought to support the projects of the older residents of preserving self-identity, self-determinacy and social relationships.

As highlighted in chapter four, a number of social activities were organised in the home for the residents. The primary organised activity was the craft group. This was run by Fiona, the activities co-ordinator, and was attended by 10 – 12 residents, generally the same ones, four mornings a week. One afternoon a week Fiona led a game of bowls in the foyer of the home, or in good weather, outside. She also took residents on trips out of the home every Wednesday. Residents took it in turns to go on runs out to the countryside, where they would generally have a sandwich and cup of tea on the bus before returning to the home. Fiona also organised occasional social events for the whole home, which were held in the foyer, such as film shows, visits from local children and music nights.

The social activities organised in the home influenced the communication of the older residents in three ways: by providing opportunities for residents to interact; by shaping the kinds of interactions they had and by giving the residents something to talk about before and after the activity. In these ways, the social activities organised in the home supported the projects of the older residents, in particular of preserving and creating social relationships. The craft group and bowls sessions, in particular, were lively events and the residents engaged in lots of conversation and 'banter'. Analysis of the data revealed that the kinds of interactions the residents engaged in during these activities were very different, reflecting the ways in which the activity shaped the interactions of the residents. Some of the interactions that the residents engaged in whilst at ·

the craft group have already been presented. As with the discussion presented in section 6.3.1 about Mary Mason entering the residents' rooms, many of these interactions were intimate in nature. Residents shared anecdotes with each other and would talk about their values and perspectives on life, as the following example shows.

> Mary Peters starts telling a story about the children from the local high school that she used to see on the bus every day when she was travelling to work after she had left school herself. She said that there was one girl on the bus that was just lovely, with her hair in pigtails, and that she couldn't stop looking at her, and had always hoped she would have a girl like that.

Interactions in the craft group were important as they gave the residents an opportunity to work to preserve their self-identity, sharing with others their thoughts and achievements. Attendance at the craft group also contributed to their self-identity and participants in this group came to be known for their craft skills. This was reinforced by the display of some of the products of the group around the home, and by the occasional raffles held to sell some items. Heather and Moira were both known in the home as good knitters, and many of the residents had bought dolls they had made. Similarly the models Alec made were displayed around the foyer. Furthermore, as the interactions presented in section 7.1.3 illustrated, through their interactions in the craft group, the residents worked together to develop a shared identity as older people who

were resourceful and resilient. As Golander and Raz (1996) found, staff members supported the self-identity of the residents by reminding them of particular achievements and reinforcing particular aspects of their character or past history through their interactions with them.

The interactions in the bowls session, although involving many of the same residents, were somewhat different from the interactions the residents had in the craft group and tended to focus far more closely on the game itself. There was a lot of banter between the residents, which was the same from week to week. The residents clapped and shouted when someone hit the jack and teased each other about the quality of the throws. The same residents attended the bowls game every week and always had the same colour balls. For example, Bobby always had the green balls as that was the colour of his football team and when he won a round everyone would shout out 'up the (name of team)'. In this way, the bowls session provided a structure through which to support the communication of the residents and help them to stay orientated towards the game. This kind of structure was clearly helpful to Ella who was able to stay fully engaged in the game, following the ball with her eyes and oohing and ahhing when someone threw a particularly good ball. Again, participation in the bowls game influenced the projects of the residents of preserving self-identity. A trophy was awarded to the winner each week to be displayed on the mantelpiece in their flat, reminding them of their bowling achievements.

The final way in which the provision of activities in the home influenced the communication of the older residents was by giving them something to talk about before and after the event. Residents would talk about what they made in the craft room, where they went on the trip and who had won the days bowls session after the event. For example, Lizzie excitedly told me about a recent trip she had been on 'to (name of town) on the bus with the pensioners'. She went on to tell me what a cold place it was and show me the clothes she had bought whilst they were away. Thus for Lizzie, this trip out supported her self-identity and sense of self-determinacy as someone who was busy, could brave the cold and choose her own clothes.

It was clear that many of the residents very much valued the opportunity to take part in activities in the home and that they were important in supporting the self-identity, self-determinacy and social relationships of the residents, as well as relieving their boredom. As Maria told me:

> 'It has been a very good day today. First the men from the church came to see me, and now you, and then there is a film show tonight at seven o'clock. I have told the woman to make sure I am there in good time. I wish every day was like this.'

It is important to note, however, that many of the residents in the home did not participate in any of the activities. For some residents this was an active choice. For example, Lizzie referred to the craft group as 'a lecture' and told me that

she didn't like that kind of thing and was too busy to go. Similarly, Maria told me that she did not attend the craft group, as it was not like the classes that she was used to. By rejecting the classes in these ways, both residents were able to preserve a positive self-identity as people who were too busy / above these kinds of activities. However, it was clear that some residents who did not take part in these activities felt their exclusion more keenly. For example, I asked Peter who was complaining of being bored why he did not take part in the game of bowls that was being set up at the time. He replied that it was not 'his kind of thing' and told me that he didn't get on with the people there. However when the game was underway he came and hovered at the back of the room watching what was going on. Indeed, there were often a number of spectators at the bowling who were never given an opportunity to join in. Thus, these activities that were so valuable to some residents, were denied to residents who were shy or whom did the staff not favour. In this way, the isolation of these residents was perpetuated and their projects threatened by the presence of the activities in the home. Residents recognised their exclusion and sought to defend their self-identity despite it. For example, Leslie justified his lack of involvement in home life telling me that he was 'new here' and hadn't fitted in yet, even though he had been in the home for some months more than other residents who were fully integrated in all the activities.

One forum that was meant to be for all residents was the 'residents' meeting'. This was a forum for residents to have a say in how the 'comfort fund' should be spent. This was a small sum of money raised from donations and sales of work

in the home that paid for entertainment, trips and extra pieces of furniture and equipment, such as new garden furniture in the conservatory. The value of these meetings in supporting the projects of the residents was unclear. None of the residents ever mentioned these meetings and when Fiona talked about them in the craft room, the residents all ignored her, suggesting a lack of investment by the residents in this process. Furthermore, Fiona reported that it was frustrating that only the residents whose key workers reminded them that they were happening, made it to the meetings and then the same voices were heard every time. These findings mirror those of Abbott et al (2000), who found that efforts to engage residents with dementia in decision making in a residential care home proved unsuccessful.

Efforts to involve the residents in the life of the home on a more day to day basis did prove more successful. Yvonne the manager would generally ask a resident to accompany her when she went to the bank or post office at the end of the road. Residents valued these trips out of the home, which made them feel important and thus supported their projects of preserving self-identity and self-determinacy. When Yvonne approached Ella to ask if she wanted to accompany her, Ella visibly grew in stature and gasped 'who, me?' before getting up to join her very excitedly. Similarly, Beatrice reported to me that she had been up the town to choose the flowers for a domestic who was retiring. Again, however, these opportunities to be involved in home life, although very valuable in supporting the projects of the residents were only open to a few of the most favoured residents.

7.2.4 Reflections

Examination of the findings highlighted the extent to which Elm View provided good person centred care and sought to support both the communication and the projects of the residents through the care regime. At least some residents had a generally positive experience in the home, felt lucky to be there and valued their interactions with the staff and opportunities to be involved in home life. Other residents, however, had a less positive experience of living in Elm View. Many residents were excluded from social activities and the informal opportunities for involvement in home life and had less positive relationships with the staff. In particular, residents who had been more excluded in life tended to be more excluded within the care regime. The care regime influenced the communication of the older residents in a range of ways, supporting the projects and communication of some residents, whilst threatening others.

7.3 Conclusions

This chapter has examined the ways in which the specific institutional context of Elm View, influenced the communication of the older residents. The chapter looked both at the ways in which the institutional facet of context influenced the communication of the residents symbolically, through the meanings they made of it, and materially, by determining the kinds of encounters the residents had in their streams of action.

When the residents interacted with the institutional context of Elm View, they were interacting with a context that was imbued with meaning 'top down' and that was designed to support both the communication and the projects of the older residents. The space in the home was carefully designed to give the residents privacy as well as to encourage the development of a sense of community in the home. Similarly the care regime sought to promote the determinacy and identity of the residents, offering them choice and being flexible to their individual needs. Some residents embraced these 'top down' meanings and enjoyed living in the home. These residents had good relationships with other residents and staff, they joined in and enjoyed the organised activities in the home and they valued the care they received. Many other residents, however, had a less positive experience in the home. Residents made a range of different meanings of the spaces and regime in the home and what one resident found supportive, another resident found threatening. Furthermore, residents who behaved in ways that other residents or staff found threatening were threatened in their interactions with others and denied opportunities for self-determinacy and to develop social relationships. Thus, residents who were most excluded and threatened in their interactions with the societal facet of context were also most excluded and threatened in their interactions with the institutional facet of context.

A key finding presented in this chapter is that although staff have a powerful influence on the communication of the older residents, both symbolically and materially, in the context of a good caring environment, other residents

influenced the communication of the residents more. These findings have profound implications for the approach taken to understand and support the communication of older people with dementia. Previous research on the communication of older people with dementia, in particular those in institutional care highlighted the key role of carers in supporting their communication (e.g. Haggstrom et al, 1998;Kitwood, 1997). However, this research shows that care staff are only one of many influences on the communication of the older residents and alone can not guarantee positive communicative experiences for all residents. Furthermore, not all residents were able to, or wanted to, engage in the activities provided by the home to support communication. Thus the social activities in the home only supported the communication of a minority of the residents. These finding highlight the importance of moving beyond reliance on carers and specific interventions to support communication and to understand the communication of each individual resident in relation to the institutional facet of context.

The implications of these findings and those presented in chapter six are discussed in more detail in chapter eight, the concluding chapter of the thesis.

Chapter 8

Conclusion

8.0 Overview

This thesis constitutes an exploration of the communication of a group of older people with dementia and living in a residential care home, in relation to their experiences and social life. Specifically, the thesis draws broadly on a symbolic interactionist approach, and through analysis of the data, develops a framework for understanding the communication of the older residents with dementia in Elm View. This framework is used to analyse the communication of the older residents in relation to their experiences of living in a care home, being an older person and having dementia, generally, and their experience of the institutional context of Elm View, specifically. In so doing, the study contributes to understanding of the experiences of ageing, dementia and institutionalisation as well as to understanding of the communication of older people with dementia living in residential care.

This chapter draws together the arguments and analysis presented in this thesis and details the ways in which this thesis has advanced understanding of the communication of the older residents with dementia. Furthermore, the implications of the findings for understanding dementia, institutionalisation, ageing and social life are discussed, as well as the methodological implications

for future research seeking to include people with dementia. The chapter is presented in three main sections. In section 8.1, the understanding of the communication of the older residents with dementia generated from the research is presented and the ways in which this understanding contributes to the field discussed. In section 8.2, the implications of the research are outlined. Finally in section 8.3, some concluding comments are made.

8.1 Understanding the communication of older people with dementia living in residential care

The key contribution this thesis makes to understanding of the communication of older people with dementia living in residential care is the development of a framework for understanding communication. This framework, presented in chapter five, breaks down communication into constituent parts and provides key concepts to inform understanding of the decisions the older residents make when responding in an interaction. Analysis of the communication of the older residents with dementia in this study, using this framework, elucidated the ways in which their communication, and the projects of the residents of preserving self-identity, self-determinacy and social relationships, was interwoven. Thus, the findings build on previous qualitative research into the experience of dementia which has shown that people with dementia have a 'sense of self' which is developed through communication (e.g. Crisp, 1995; Sabat, 2003).

The second key novel contribution of this thesis to understanding the communication of older people with dementia in residential care is to outline the ways in which the context influenced their communication. Specifically, analysis of the data revealed two key facets of context that were particularly important in influencing the lives of the older residents in Elm View. These were the societal and institutional facets of context. These facets influenced the communication of the older residents materially, by determining the kinds of stimuli they encountered in their interactions within them, and symbolically, through the meanings the older residents made with and within these facets of context. As discussed in chapters six and seven, the extent to which the meanings that the older residents made in these contexts threatened or supported their projects, influenced the ways in which they responded to these meanings, and therefore their communication.

The analysis presented in this thesis, highlights the many ways in which the projects of the older residents were threatened and supported by the meanings they made with, and within, the societal and institutional facets of context. The residents had spent their lives interacting in a societal context that viewed ageing, dementia, frailty and institutionalisation with fear and stigmatised these aspects of experience. Thus, when the residents made meaning of themselves in interaction with the societal facet of context, they interacted with these very threatening meanings. Furthermore, the meanings made in interaction with and within the societal facet of context coloured the meanings they made with and within the institutional facet of context. This meant that many of the meanings

the older residents made in interaction with and within the institutional context were threatening, even though the context itself had been carefully designed to support the projects and communication of the older residents.

Examination of the responses of the older residents to these meanings revealed that meanings that supported the projects of the older residents also supported their communication, enabling the residents to continue with their intended stream of action. When the communication of the older residents was supported in this way, they were observed to engage in rich and varied interactions and the impact of their cognitive impairment on their communication was easily overcome. Thus, the findings highlight that when people with dementia are in a context that they make meaningful as being supportive to their projects, they are able communicators. More often, however, the residents were threatened in their interactions. The residents responded to these threats in a number of ways.

Residents, who were threatened in their interactions, were sometimes able to reject those meanings, thereby resisting the threat to their projects. However, the discussion presented in chapters six and seven revealed that this was a difficult and lonely strategy that often led the resident to be threatened in subsequent interactions. More commonly, residents who were threatened in their interactions accepted those threatening meanings. Having done so, the residents tended to respond in one of three ways, by being silenced, by working

to preserve their projects despite the meaning or by rejecting the application of the meaning to themselves.

The analysis presented in this thesis provides many examples of residents who were silenced by the meanings they made in their interactions, and who were unable to respond to defend their projects. These interactions constituted the ultimate threat to both the communication and the projects of the residents. Thus, despite the excellent person centred care provided in Elm View, what Kitwood termed the 'personhood' of the residents was still profoundly challenged from time to time in this setting. At other times, however, the older residents were able to redress the impact of the threatening meanings by working to preserve their projects in other ways. For example, the residents countered negative discourses around ageing, by highlighting achievements in their work or personal life. Use of this strategy was central in the efforts of many of the residents to negotiate a good quality of life in the home and was something that the home sought to support, for example by providing opportunities to reminisce and encouraging the residents to 'make the best of it'.

The final way in which residents responded to threatening meanings was to accept the meaning in principle, but to reject the application of that meaning to themselves. In these cases, residents sought to distance themselves from the meaning. This made living in a residential care home, surrounded by other residents who embodied the very threatening meanings that the residents were

seeking to avoid, particularly challenging. The many different strategies the residents engaged in to distance themselves from residents whom they perceived to embody these threatening meanings have already been described. These strategies, which varied from constructing other residents as objects of pity, to verbal abuse, were damaging, not only as they threatened the projects of other residents, but also as they perpetuated the threatening nature of the meanings in the home. For example, the efforts of the residents to distance themselves from dementia ensured that societal discourses around dementia were firmly reproduced in the home. Thus, the efforts of the residents to defend their self-identity, self-determinacy and social relationships from the impact of the threatening meanings they made of their life as an older person with dementia in a care home, served to perpetuate these meanings and to reproduce processes of marginalisation and exclusion occurring in the societal context in the home.

8.1.1 Implications for understanding the communication of older people with dementia in residential care

The understanding of the communication of older people with dementia in residential care presented in this thesis constitutes somewhat of a departure from previous research on the communication of older people with dementia. Utilising a symbolic interactionist approach to understanding communication and social life, this thesis has developed an understanding of communication and dementia which is firmly grounded in the perspectives of the person and is

mindful of the context in which they live. In so doing, the thesis advances understanding of communication in several key areas.

Firstly, the research shows that although people with dementia may experience specific communicative problems, within a supportive context they are able communicators, adopting a range of strategies to successfully negotiate interactions. Therefore, these findings clearly challenge the deficit view of dementia as perpetuated by much quantitative research in the area (e.g. Bourgeois, 1991; Mentis et al, 1995; Ward et al, 1992). Secondly, although the interactions that the older residents in Elm View had with staff were important to their communication, and in particular threatening interactions with staff tended to silence the residents, the residents engaged in many different strategies to negotiate interactions and to preserve their projects that were not dependent on staff. Thus, the findings challenge the tendency, in much of the previous research on communication and dementia, to construct carers as central to the maintenance of the communication of older people with dementia (e.g. Hellner and Norberg, 1994; Kitwood, 1997). Furthermore, in a good caring context, such as Elm View, residents had a lot of opportunities to interact with other residents. In Elm View, the interactions between residents had a far greater influence on the communication of the older residents than the interactions between residents and staff. By examining these interactions and relationships in detail, the thesis makes a significant contribution to understanding of the communication of older people with dementia, as to date, interactions between older people with dementia have been largely ignored. Thus the findings

highlight the need to look beyond the role of staff in shaping the communication of the older residents and focus on how people with dementia negotiate their interactions in the world.

8.1.2 Implications for policy and practice

These findings have two key implications for policy and practice to support the communication of older people with dementia in residential care. Firstly, and most importantly, the findings highlight that the communication of the older residents with dementia can not be supported by good care alone. Excellent care is an essential prerequisite to the development of a supportive context that enables the person with dementia to negotiate the communication difficulties they experience. However, this excellent care must be provided within a societal context that values older people and understands dementia in the same way as physical disability among younger people is coming to be understood, as just another part of life to be got on with (Watson, 2002). Embracing this insight demands that policy and practice to support the communication of older people with dementia in residential care goes beyond seeking to provide good care and seeks to reddress both the structural inequalities and cultural processes that perpetuate the marginalisation and exclusion of older people with dementia in society.

This is obviously a very challenging enterprise, and one that can not be taken forward through the publication of care standards or best practice guidance alone. However, the social model of disability, outlined in chapter two, provides

a framework for action, for researchers, policy makers, practitioners and people with dementia seeking such change. Further research is urgently needed to explore the applicability and potential of this model for advancing the social inclusion of older people with dementia. Furthermore, it is vital that the field of dementia goes beyond the rhetoric of conceptualising dementia as a disability and strives towards the development of a new social understanding of dementia that has social change at its core. This thesis contributes one small, but important step, to this end.

The findings also have implications for the ways in which care is planned and provided for older people with dementia in residential care. Throughout the data analysis, the extent to which the older residents were individuals, bringing diverse perspectives to make meaning in the setting, was highlighted. This meant that interventions and features of the care provision in Elm View that were supportive to one resident, were threatening to another. Thus, the residents had very different experiences in Elm View and whilst some residents, whose perspectives and preferences fitted with those of the home, enjoyed very good quality of life, other residents were excluded and threatened. These findings highlight the need for care regimes to take 'person centred care' one step further and provide truly individualised care to the residents. Again, this is not straightforward, and demands that space is created in the regime for the voices of all the residents to be heard, and for many different kinds of interests and perspectives to be accommodated. Research reviewed in chapter one highlighted that working to 'hear the voice' of older residents with dementia was

a time consuming endeavour (Allan, 2002) and analysis of the findings in this study highlighted that the residents who had the worst quality of life in the setting were the ones who were most often silenced in their interactions with the regime. Furthermore, the very meanings associated with living in a care home squashed the self-determinacy of all the residents, making them less able to see how life in the home might be improved.

The framework presented in chapter five provides the basis of an approach that could be used in care settings to understand the communication of the older residents in relation to their experiences in the setting and intervene to support the projects of the individual residents accordingly. Development of such an approach, although beyond the scope of this thesis, constitutes an important area for future research.

8.1.3 Summary

The aim of this thesis is to explore the influence of living with dementia in a residential care home on the communication of the older residents. In this section, a concluding account has been presented which has emphasised the very significant influence that living with dementia in a residential care had on the communication of the older residents. The diverse meanings that the older residents made of living with dementia in Elm View were highlighted and the extent to which many of these meanings threatened the projects of the older residents, outlined. The ways in which the older residents responded to these meanings through their communication were then considered in detail. Finally,

the implications of the findings for understanding communication and dementia and for supporting the communication of older people with dementia in residential care were discussed.

The implications of the research more generally for understanding dementia, institutionalisation, ageing, social life and for research seeking to include people with dementia are considered in the following section.

8.2 Implications of the findings

The primary concern of this study was to develop an understanding of the communication of older people with dementia living in residential care. However the approach taken to the research meant that the study also elucidated aspects of the experience of dementia, ageing and institutionalisation specifically as well as social life generally. The implications of the research for understanding in these areas, as well as some methodological implications of the research are examined in this section.

8.2.1 Understanding dementia

In chapter two of this thesis, it was argued that a new understanding of the experience of dementia was needed that was theoretical and considered the experience of dementia in relation to processes of marginalisation and exclusion. The research presented in this thesis supports this assertion and outlines the profound ways in which the experience of dementia is influenced by

processes of marginalisation and exclusion operating in the societal context. Thus the research shows that it is no longer possible for the field of dementia to ignore the marginalisation and exclusion of people with dementia and to perpetuate the construction of people with dementia as objects of care. It is time for a new 'social model' of dementia, which looks beyond the immediate psycho-social context of the residents to examine their experience in relation to broader social processes. Such a model must be theoretical, critical and grounded in the experiences of people with dementia themselves. Furthermore, it is vital that the rhetoric in the field of dementia changes from, seeking to provide person centred care, to promoting the social inclusion and citizenship of people with dementia.

This thesis contributes to this change, by providing evidence for the impact of broader social processes on the experience of dementia, and by providing a framework for understanding a vital aspect of the experience of dementia in relation to these processes. Future research in this area is needed to explore more explicitly how older people with dementia experience and construct marginalisation and exclusion and to identify barriers to, and best practice in, participation and involvement of people with dementia in society.

8.2.2 Understanding institutionalisation

The literature reviewed in chapter two highlighted the extent to which institutionalisation is problematic (e.g. Foucault, 1977; Goffman, 1961; Patterniti, 2000). This research supports these findings and reveals that

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regardless of the quality of care provided in the home, the meanings the residents made of being in a home were so overwhelmingly negative, they coloured all other experiences in the home. Furthermore, the circumstances surrounding the move to the home for many residents were very threatening, which made settling into the home and finding a routine within it more difficult.

It is important to reiterate that some residents did experience institutionalisation very positively. There were many opportunities in the home for the residents to engage in social interaction with other residents, to assert their self-identity and self-determinacy, and to foster social relationships with others in the home. However, the ability of the residents to make the most of these opportunities was contingent on their having the social skills and confidence to participate in the group activities in the home and having personal belongings to bring into the home to create a private space that was supportive to their self-identity. Furthermore, having a strong social network outside the home and a prestigious personal biography also supported the residents to make the most of life in the home. Thus residents who were socially excluded and marginalised outside the home continued to be excluded and marginalised inside the home.

On a very pragmatic level, these findings highlight the importance of developing a range of models of institutional care, to support the needs of a diverse population of older people, with and without dementia. However, more fundamentally the findings call into question the policy of providing care to many older people with dementia in groups. The findings show that, not only do

residents feel the stigma of 'living in a care home' keenly, but that group living is something that is very difficult to negotiate requiring a range of resources. It is paradoxical that older people living in residential care tend to be the most excluded and have fewer resources to bring to negotiate life in the home than those older people whose needs are met in the community. Again, these findings highlight the need for social change more generally, to address the ageist policies and practices that firstly result in the social exclusion and marginalisation of older people, and secondly that lead to their needs being met in institutions.

8.2.3 Understanding the experience of aging

In chapter two the extent to which ageing was feared and stigmatised was highlighted (e.g. Elias, 1985; Matthews, 1979), and the opportunities for the inclusion of older people in a post-modern society discussed (e.g. Featherstone and Wernick, 1995; Gilleard and Higgs, 2000). This research presented in this thesis found that relative to having dementia or living in a care home ageing in and of itself was an unproblematic experience. Although the older residents bought into negative discourses around ageing, they continued to maintain a positive self-identity as an older person. Furthermore, the residents worked together to construct age in terms of wisdom and achievement, as opposed to failure and frailty. Thus, 'being an older person' was not stigmatised in the home, however the reflections of the older residents suggested that they did experience ageing as a mask. This led, at least some of the residents, to work

hard in their interactions to present the true, youthful, sexual, competent self, behind the mask of ageing.

The ways in which residents experienced frailty, however, was much more threatening to their projects and therefore communication. Despite the good care provided in the home, residents were very anchored by the meanings they made of their frailty and were unable to incorporate being frail with their project of preserving self-determinacy, in particular. In this way, experiencing physical impairment in later life in the context of a care setting is much more disabling than recent research has shown living with an impairment in society is (Watson, 2002). These findings highlight the need for death, disability and disease in later life to be made more visible in society and highlight the ways in which the drive to healthy ageing exacerbate the marginalisation and exclusion of those who can not live up to this ideal.

8.2.4 Understanding social life

This thesis constitutes not only a study of the communication of older people with dementia living in residential care, but also a study of social life in general. Thus the research has key implications for understanding and researching social life. The research has highlighted that processes of marginalisation and social exclusion occurring at a societal level impact on the everyday lives of older people with dementia in very profound ways. By merging symbolic interactionist and more critical perspectives, the study has shown that the meanings that social actors make of themselves through their interactions in the

world are intimately tied up with broader societal discourses and structures. Furthermore, through the development of the framework, and in particular, the concept of projects, the study has elucidated an understanding of how processes of marginalisation and exclusion are reproduced in day to day interactions in the world, and how social actors respond to these. Thus, the study highlights the importance of Foucault's (2001) concept of 'self-subjectification' and provides many examples of the ways in which the older residents embraced and perpetuated their subjectification through their interactions with each other, as well as with the institutional and societal facets of context.

This finding has important implications for understanding how processes of exclusion and marginalisation might be redressed more generally. Foucault (2001) argued that it is only when people are aware of their subjectification that they can resist it. Thus, social change to promote the social inclusion and citizenship has to come from the bottom up, as well as the top down. However, the older residents in Elm View with a couple of exceptions were unable to see their exclusion and marginalisation and exclusion, let alone resist it in those terms. The residents did, however, engage in many acts to resist micro-level processes of exclusion and marginalisation occurring in the home. Gaining an understanding of these processes provides a vital first step in understanding the ways in which social actors experience, construct and negotiate processes of social exclusion and marginalisation more generally.

8.2.5 Methodological implications

The findings raise many questions about what it means to involve people with dementia in research. Analysis of the recordings shows that through the use of an inclusive methodology, residents with dementia were clearly engaged in the research and interpreted meaning from it. Despite all my best efforts, however, the understandings the residents reached of the research, and in particular of the broader research aims, did not always correspond with my own. In many cases, residents clearly consented to research they did not understand. Given both the cognitive impairments experienced by people with dementia, and in general their lack of experience of being involved in research, this situation is inevitable, and poses a challenge for the future involvement of people with dementia in research.

Current conceptualisations of participatory and emancipatory approaches to research and medical and social science ethics guidelines all place participant informed consent at the centre of ethical research practice (Dewing, 2002). However, findings from this study highlight the incongruity of imposing such a cognitively driven and abstract conceptualisation of good practice on people with dementia, going against all the principals of person centred care. In this study, restricting the research to involve only those who gave informed consent would not only have prevented the recording of the experiences of many people with more advanced dementia, but would have precluded their involvement in the research process, leaving the participants disempowered either way. This is not to deny the importance of informed consent in research, but merely to

highlight the problems inherent in this approach and the need to find new ways of conceptualising research if, as a field, we are committed to the involvement of people with dementia.

A first step towards finding a new way of conceptualising research that might ethically and meaningfully include people with dementia, is to examine the meanings of involvement to them. Analysis of the video recordings and field notes enabled interpretation of a number of meanings for the residents of being involved in research. These are summarised in table 8.1 alongside the meanings for the researcher of involving the residents in the research.

Table 8.1. Meanings of involvement for the researcher and the research participant.

Nature of Involvement	Meaning for Researcher	Meaning for Research Participant
Awareness that being researched	Avoids disempowerment and 'othering' of participants	Provides opportunity to show "best side" to the camera
Understanding of research process and aims	Enables informed consent	Gives status and sense of satisfaction / achievement
Informed consent to research	Meets requirements of ethical committees	Provides opportunity to exercise choice and self-determination
Participation in data collection and analysis	Avoids disempowerment and othering	Provides opportunity to show "best side" to the camera.

Comparison of the two columns highlights the abstract concerns of the researcher on the left as opposed to the very personal concerns of the

participants on the right. As a researcher, I was motivated by theoretical and ethical understandings of research and the requirement of research ethics committees. However, involvement afforded the older residents with dementia, choice, status and some determination in the ways in which they were represented. Indeed, this finding is supported by the experiences of James McKillop and Elaine Robertson, whose chapters on the benefits of being involved in research highlight the importance of value, respect and relationship with the researcher and made no mention of ethics or guidelines (McKillop, 2002; Robertson, 2002).

8.3 Concluding comment

This thesis tells the story of a research journey. The research started by examining an old issue in the field of dementia, the 'problem' of communication and dementia, and through the application of first, a new method, then, a new methodology and finally, a new theoretical framework, arrived at a new conclusion. That is, that the 'problem' of communication and dementia is not primarily located in the people with dementia themselves, they continue to be able communicators despite their cognitive impairments, but is located in the social contexts in which they live. As outlined in this chapter, this finding has profound implications for both understanding the communication of older people with dementia in residential care and for policy and practice that seeks to support their communication.

The research findings highlight the need for the field of dementia research to move forward and examine all aspects of the experience of dementia in relation to the social contexts in which people with dementia live. This research needs to be grounded in the experiences of the people with dementia themselves, and the meanings they make of those experiences. As the story that is told in this thesis has shown, this is not a straightforward endeavour and demands that the research is exploratory, inclusive, reflexive and draws on understandings and theories of everyday life. Such an approach to research takes time and demands that the researcher embraces the slippery and nebulous nature of experience, as opposed to seeking to reduce and generalise it.

The findings presented in this study also have profound implications for policy and practice that seeks to redress the 'problem' of communication and dementia. The findings highlight the need to move from thinking in terms of how we can treat, or care for people with dementia, and instead think how we can change society so that people with dementia can be fully included in it. This is not to deny the value of the development of drugs for dementia, nor the need to provide excellent care for people with dementia, but instead to see treatment and care as just two small parts of a larger move towards full citizenship and inclusion for people with dementia.

In chapter two of this thesis, the move within the field of dementia from a purely biomedical understanding of dementia towards a social understanding of dementia was documented. Central to this move was recognition of the ways in

which the medicalisation of dementia subsumed the individuals concerned so that all aspects of their experience came to be understood in relation to their dementia. The development of Person Centred Care was central in redressing this trend and in making visible the person with dementia. However, this image of the person with dementia is still very partial, and people with dementia are still made objects of care. The findings of this study herald the need for the next shift in the field of dementia, from seeking to provide good care to people with dementia to working to promote their social inclusion and citizenship.

Appendix A

Cook, A (2002) Using video to include the experiences of people with dementia in research. In Wilkinson, H., (Ed.) *The Perspectives of People with Dementia*, London: Jessica Kingsley

Chapter 12

Using video observation to include the experiences of people with dementia in research

Ailsa Cook

Introduction

The recent social policy focus on providing people with dementia with good quality of care has resulted in a drive to find ways to include their experiences in research. These moves have led to a body of researchers experienced in including the perspectives of people with mild dementia in their research (see Allan 2000; Pratt and Wilkinson 2000). To date, however, the experiences of people with moderate and advanced dementia have largely been excluded from research, as it is not known how to facilitate interaction with this group of people with often profoundly impaired communicative abilities.

Much of the research that has sought a window into the lives of people with more advanced dementia has examined their behaviour using systematic observation measures (e.g. Bredin *et al.* 1995; Van Haitsma *et al.* 1997; Ward *et al.* 1992). One of the most widely used of these measures is Dementia Care Mapping (DCM), where the behaviours of people with dementia are coded by an observer into predefined categories, to give a picture of their quality of experience in care (Bredin and Kitwood 1995). This and other systematic observation measures, such as Bowie and Mountain (1993), are limited in that they can only capture aspects of a

person's experience as they fall into the predefined categories of behaviour. This research, therefore, cannot offer radically new understandings of the experience of dementia, but merely modify the view of dementia reflected in the researcher's choice of which categories of behaviour to observe.

The reliance on these systematic observation measures has arguably helped to perpetuate a medicalised view of the lives of people with dementia as recipients of care and interaction, be it good or bad. These preconceptions are being challenged by the participation of people with early dementia in the research process and its dissemination (see chapters in this book by Robinson and McKillop). There is, however, an urgent need to find ways to include the experiences of people with dementia in research who are unable to articulate their perspective themselves. This will enable the development of a more realistic and useful model of the experience of dementia with which to inform social care policy and practice.

This chapter describes a research project that used video to include the experiences of people with dementia in research. Specifically the project sought to examine the non-verbal communicative experiences of attendees at a dementia-specific day care centre with varying degrees of cognitive impairment, from mild to fairly advanced. Two researchers observed naturally occurring interactions in the setting using both pen and paper and a video camera to record the observations. Review of the literature on video observation and dementia revealed that it has been used mostly by Scandinavian researchers to examine several aspects of dementia. These include: facial expression (Asplund, Jansson and Norberg 1995; Jannson et al. 1992); problems with feeding (Athlin et al. 1990; Philips and Van Ort 1993); differential response to stimuli (Norberg, Melin and Asplund 1986); the effectiveness of staff training (Kilhgren et al. 1996); and carers strategies for understanding people with dementia (Haggstrom, Jansson and Norberg 1998). Video has been shown to be useful for examining aspects of interaction with people with dementia, and for helping carers reflect on their care. These studies have not, however, used video to explore the experiences of people with dementia other than as they relate to their carers. In addition, none of the studies used video to include the participants with dementia in the research process.

The use of the video-recorder in this study was found to enable the inclusion of the participant with dementia's experiences in the research in two ways. Naturally occurring interactions were video-recorded, providing a detailed and permanent record of the participants' experiences as reflected by their behaviours. These video-recorded observations were not limited by any predefined categories and were analysed qualitatively allowing understandings of the communicative experience to come from the data. Second, the use of video enabled the participants with dementia to be involved in the process of data collection and analysis. The use of a small, light video camera encouraged participants to be involved in the process of filming, and showing the participants the video recordings enabled their interpretations of the behaviours recorded to be included in the research.

This chapter will describe the process of video-recording interactions, including negotiating access to do the research; gaining consent from the participants to be recorded; using the camera; transcribing and analysing the data gathered; and using the videos to elicit interpretations of the interactions from the participants. Problems faced when gathering the data will be discussed. Ethical issues related to capturing and storing the image of someone with dementia will be discussed, in particular as they relate to dissemination of research.

Starting out, negotiating access and gaining consent to do research using video

Before research examining the experiences of people with dementia can be carried out, access must be negotiated with several gatekeepers. Using video to record the daily life in a service setting for older people with dementia is a potentially sensitive enterprise, and it is important to anticipate concerns that gatekeepers may have when negotiating access. The process of negotiating access in this study involved two sets of gatekeepers, the service manager and the social work department, both of whom had similar concerns. These included: the potential intrusiveness of the camera in the setting; how consent would be obtained for the residents with dementia; the extent of staff involvement in the study; that the partici-

pants, anonymity would be preserved; and what would happen to the tapes after the research. In addition the service manager was insistent that the relatives be informed of the research, which she said was vital to maintain their continuing cooperation and trust in the service. The social work department also considered how useful the research might be to their work and were keen that the research findings be disseminated to them, including feedback on the success of the consent protocol and other arising ethical issues to be considered when reviewing future research proposals.

After access had been negotiated with the service manager and social work department, a meeting was held with the staff in the service to explain the study and find out if they were willing for it to go ahead in their service. Although it would have been hard for the staff to reject the project altogether, given that they knew it had the support of their manager, this meeting did enable them to highlight concerns they had about the project. In particular, the staff were keen to know what would happen with the videotapes after the study and who would get to see them. They also wanted to know if the project would interfere with their work in any way. Finally several of the staff said that their performance on camera may not reflect the way they normally worked and worried that they would be unable to relax whilst the camera was on.

It is notable that the service users with dementia had no say in whether the project was allowed to go ahead in the service. Instead they were given the option to consent or otherwise to take part in the study, once the approval of the other parties had been given. In this way, the negotiation of access process denied them the chance to say whether they wanted the research project in their service and so actively disempowered them. This situation arose because the researcher could not have access to the attendees to ask them if they were willing for the research to go ahead until access had been agreed with the other gatekeepers.

Having negotiated access with the gatekeepers to carry out the research in the project, individual consent was sought for the attendees in the day centre. In the first instance the researchers approached the attendees formally to tell them about the study and asked if they would be willing to take part. An information sheet was prepared for the participants

were only approached for consent after the participant with dementia had indicated that they were willing to take part.

Written informed consent was obtained from the staff members of the service. They were given an information sheet to keep and were reassured that they could decide not to be video-recorded at any time if they chose.

Recording the interactions

Before video-recording interactions, the researchers spent time in the service, joining in the activities and making pen-and-paper observations about the communication occurring in the day centre. Informal consent was regularly negotiated during this time and the participants were involved in observing each other. In this way they began to develop an understanding of the study and the researchers' role in the day centre. This period spent observing and chatting to the participants with dementia and the staff proved essential to the smooth introduction of the video camera to the day centre.

Video recordings were then taken of naturally occurring situations. The researchers based their decision as to which interactions to record on convenience and interest. Before recording an interaction, the researchers would approach the group and explain that they wished to record the activity. The camera was passed round so that the participants with dementia could record each other and get a feel for what being part of the project was like. The participants were told that if they chose, they could watch the video the following week. They were also reassured that the video camera could be turned off at any time if they wanted. Having obtained the consent of all the participants, both those with dementia and the staff, one of the researchers joined in the group and took some notes whilst the other video-recorded the action.

The room that the activities were conducted in limited the filming to a degree. The room was quite cramped, and therefore not all of a group could be recorded at once. This problem was overcome by moving with the video camera to record different groups of individuals in turn. Ideally the camera should be positioned with natural light behind it, about two metres from the subject of the picture; however, the quality of the digital

handheld camera meant that good pictures were obtained from all angles and distances. The recordings focused primarily on the person at the centre of the interaction at the time, and included as many as possible of the other participants. The camera had a good quality zoom, so close-up shots of participants' facial expressions could be taken as needed without placing the camera near their faces.

During the video recordings the participants were reminded of the presence of the camera and asked if they were willing for recording to continue. Often the participants had forgotten about the camera, and always said that they were happy for it to be there. Although they were not bothered by the camera, the participants with dementia did signal when they wanted the interaction that was being recorded to end, either by saying so, when asked, or by getting up and leaving. The staff, however, did seem more conscious of the presence of the camera, and were recorded glancing at the camera from time to time, which is something that the participants with dementia never did.

Reviewing interactions with the participants

The participants with and without dementia were asked after the recordings if they would like to watch the video. This was done on a different day, as the film had to be copied onto standard videotape to be played through the day centre's video player. Access to a more modern television in the setting would have enabled the videos to be shown immediately after the recording as the camera could have been plugged into the back of the television. The videos were only shown to the people who participated in the recording, if everyone in the recording agreed that they were willing for the videos to be shown. In one case a participant clearly stated, when asked, that he did not want to see the film, but said that he was happy for the staff member recorded and the researcher to watch it together.

Reviewing the videos enabled the participants with dementia to provide interpretations of specific interactions and behaviours recorded on camera. In one instance, four participants with dementia and two staff were video-recorded playing a board game. When asked, all participants said they would like to watch the video the following week. Three of the

four participants with dementia could identify themselves and each other, however the fourth participant identified everyone else, but did not identify herself. She did however mimic her gestures on the screen, and no one else's, suggesting that she knew at least at some level that this was her. When asked, the attendees identified behaviours such as whispering in the ear to another, and interpreted this as cheating at the game. The participant who didn't acknowledge her presence on the screen still offered interpretations of her behaviour. She interpreted her gesture of sitting with her hands covering her face when not able to answer a question as 'hiding'. Similarly one participant identified another's elaborate hand movements when rolling the dice as 'his banter'. These interpretations were useful as they confirmed the researchers' interpretations and showed that the participants could pick up on subtle social cues in the interaction, even if they couldn't remember the interaction happening, and couldn't identify themselves.

Showing the videos to the staff also enabled them to offer their interpretations of the communication observed. When shown the video, they were able to reflect on the interaction in depth, and identified which parts they were pleased with and what they would have done differently a second time. One staff member questioned his use of a book during the interaction and noticed how his physical positioning had been hindering the conversation. He also commented on the success with which he had reinforced some of the participant's non-verbal behaviours and had let her keep talking even though he hadn't fully understood the meaning of what she was saying. These interviews were tape-recorded for later transcription and analysis.

Some of the staff involved in the review process reported that this procedure was beneficial to their practice. Watching the video recordings enabled them to reflect on their behaviour and look at their communication in a different way. During the review process staff reflected on their communication in a critical and positive way and developed more sophisticated understandings of the interaction than they had been operating with during the interaction itself. One of the attendees, however, found the review process unsettling, possibly because she was aware that she was on the television, but had forgotten being filmed and so how she had got

there. This unease may have been lessened if the researchers had been clearer when introducing the activity to the attendees.

Transcription and analysis

The transcription and analysis process started by reviewing the videotapes to determine the types of interaction occurring. Excerpts from the video recordings containing notable examples of different types of interaction were then transcribed verbatim. These transcriptions included verbal and non-verbal communication, physical positioning of the participants, and context of the interactions, including what was happening before the video camera was turned on. Three layers of extra information were then added to the transcriptions. First, the researchers' interpretations of the observed behaviours were included; for example that Sidney is playing with the dice to draw attention away from the fact that he doesn't know the answer. Second, the interpretations of the participants were added, in this case that the game with the dice was his 'banter'. Finally the reflections of the interaction partners without dementia prompted by this episode were included.

The process of producing a transcript in this way is very time-consuming, but has the advantage that the experiences of the people with dementia in the frame can be examined in detail. It also allows for the interpretations of the communication of both the participants with and without dementia to be included in the research. This depth of analysis enabled the development of a complex picture of the experience of dementia in this setting. The understandings that emerged following this process included a picture of the participants showing nerves as their turn in the game came, and using primarily humour to hide the fact that they didn't know the answers. Less impaired participants were observed to add to the humour by colluding with them and telling them the answers. Non-verbal gestures were used to both answer questions, such as miming of swimming, and to distract people's attention from their failure to answer the questions. Staff and participants with dementia used non-verbal behaviours to support and reassure each other as they struggled to find the answers.

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and emphasises their 'otherness', thereby adding to their exclusion and disadvantage (Fine 1994). Previous research using video to investigate aspects of dementia has been guilty of this, by using the camera to examine the experiences of the 'subjects' as if they were in a goldfish bowl. Smith (1995), for example, video-recorded people with dementia and 'normal controls' watching video clips and analysed the recordings using a coding schedule to see if people with dementia (viewed as a homogenous, diagnostic group) responded to others' emotion with facial expression. In this way the research objectified the individuals involved as members of a diagnostic category with a specific communicative dysfunction. Fine (1994) stresses how this type of research objectifies the participants and serves to add to the exclusion that disadvantaged groups face. Instead, she calls for researchers to include the participants' voices in research and emphasise the heterogeneity of their experiences. Therefore it is essential, if the research is to facilitate inclusion, that the participants' perspectives are ascertained wherever possible.

This research sought to include the perspectives of the participants by showing them the videos and asking them to offer interpretations of the interactions recorded. It is important, however, that the video recordings of the participants with and without dementia are not shown to families or other people in that setting, unless they too were involved in the interaction. Participants with dementia in our recordings were observed to use humour and gestures in ways that might appear to be childlike or crude when taken out of context, and staff were seen to encourage these forms of expression. Showing these recordings to others involved in the setting, but not that particular interaction, leaves both the staff and attendees open to judgement and may prevent the participants from continuing to express themselves in ways which may be unacceptable in other settings. In particular, families may be unwilling to accept the ways in which their relative behaves when in a day-centre setting with others of their own age as opposed to in the family home.

Given the potentially stigmatising nature of a diagnosis of dementia, it is equally important that the images of people with dementia are not shown to people in the wider community, unless permission is expressly given from the people with dementia themselves. The powerful visual

images captured on camera could be used to enhance the dissemination of the research, for example in conference presentations or training videos; however, this both identifies who the research participants are and that they have dementia. This means that it is no longer within the person with dementia's control who does and does not know their diagnosis. Furthermore, that person is inherently linked to any interpretation that the researcher puts on the data, regardless of whether he/she agrees with it or not. Putting images of people with dementia on the internet is potentially even more damaging, as it not only increases the numbers of people who may identify that individual as having dementia but unless extreme care is taken, others may download the image and use it in ways neither the researcher nor the participant can control.

The ethical issues surrounding the dissemination of research have led the research team to consider alternative methods for representing the interactions recorded in the project, so that the findings may be presented visually without compromising the anonymity of the participants. Pilot work is in progress at the University of Stirling in conjunction with the Royal Scottish Academy of Music and Drama to determine the possibility of using actors to represent the observed interactions. Older actors will be shown excerpts of video and asked to reproduce the interactions seen. This is a costly and time-consuming process, which includes writing storyboards, hiring a director, actors and film crew, organising costumes and make up, editing the films and transferring the material onto CD-ROM and video. Once completed, it is hoped that the films may be used to disseminate the findings visually in online papers, conference presentations and training materials.

Conclusions

Video observation can be used to include the experiences of people with moderate and advanced dementia in research. Using video observation not only made it possible to document and analyse in depth the experiences of people with dementia, it also facilitated their participation in the research process. Furthermore, review and analysis of the video recordings enabled the researchers and participants to reach a deeper understanding of the

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Appendix B

Cook, A. and Hubbard, G. (2000) Using Video to observe non verbal communication amongst people with dementia. *Proceedings of the Annual Conference of the British Society of Gerontology, Oxford.* p241-244.

USING VIDEO TO OBSERVE NON VERBAL COMMUNICATION AMONGST PEOPLE WITH DEMENTIA

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Abstract

The potential for communication with people with advanced dementia is well documented (e.g. Killick and Allan, 1999). Although much has been written about the depth of interaction that can be achieved with people with dementia and limited verbal skills, there has been no systematic investigation into the ways in which this is accomplished. There is a need for detailed analysis of interactions between carers and people with dementia to determine the strategies/communicative behaviours used to facilitate communication with this population.

Dementia is often accompanied by language impairment, leaving the person more dependent on non-verbal channels of communication. Video can be usefully employed to capture the non-verbal component of interactions and enables detailed analysis. Previous research has shown that video can be used to record interactions with people with dementia in naturalistic settings (e.g. Asplund et al, 1995), however this type of research is very much in its infancy.

Pilot work was conducted to explore the non verbal communicative behaviours of people with dementia in a range of settings. One aim of this pilot work was to investigate the extent to which video recording can be used, by researchers, to gain understandings of people's non verbal communication. People with dementia were observed in a range of settings by both participant observation and using a video camera. Field notes from the participant observations were used to assess the quality of the data recorded, and to inform the analysis. Reports were elicited from both carers and people with dementia as to the acceptability of the video camera.

Ethical and consent issues particular to using video to research communication and dementia are discussed.

Introduction

Due to an increase in the numbers of people with dementia and a burgeoning commitment to providing this population with good quality care, dementia is an area of growing concern for the areas of health and social care policy. Recent policy emphasis on quality of life issues requires a move towards finding ways to support people with dementia and involving them in the services they receive. To date, people with moderate and severe dementia have been excluded from both user involvement programs and many innovations in social care because it is not known how to facilitate communication with this group of people with often profoundly impaired verbal abilities. It is vital therefore to find ways of eliciting these people's views and facilitating their inclusion in everyday life to improve their quality of life. From a social policy and practice perspective, greater understanding of nonverbal communication is essential to improve communication with this excluded group of people.

There is considerable evidence that communication involves not only the words which are spoken as part of an interaction but also a vast array of other audio and visual signals, e.g.: the pitch and intonation of the voice; gaze; gesture; posture; and changes in facial expression (e.g. Goldin-Meadow, Wein & Chang, 1992; McNeill, 1985; Doherty-Sneddon, et al, 1997). Such nonverbal communication transmits a variety of information including emotional and speech/language related information. The utility of nonverbal communication in interacting with people with advanced dementia has been noted by carers working with people with dementia, and has lead to the development of therapies which "tap into" nonverbal channels, such as music therapy (Aldridge, 1996), and movement therapy (Crighton, 1998).

Empirical research on communication and dementia is dominated by studies documenting communication deficits. The large practice literature describing how communication with people with dementia can be achieved (e.g. Killick and Allan, 1999; Perrin and May, 1998) has not yet been

matched by research. There is a need for detailed analysis of the communication of people with dementia to elucidate the strategies and behaviours used to facilitate communication with and by this population. Given the importance of non verbal communication in dementia, the use of video is proposed as an ideal tool to capture both the visual and audio aspects of interactions. Video recordings also allow for the detailed analysis of the observed interaction, which is essential if the complexities of communication amongst people with dementia are to be unraveled.

Video has been used to record interactions with people with dementia in naturalistic settings. Researchers studying dementia have used video recordings of interactions to examine: facial expression (Asplund, et al 1995 and Jannson et al, 1992); problems with feeding (Athlin et al 1990 and Philips and Van Ort, 1993); differential response to stimuli (Norberg et al, 1986); the effectiveness of staff training (Kilhgren et al 1996); and carers strategies for understanding people with dementia (Haggstrom, et al 1998). Despite extensive debate on the effect of video recording the interaction studied (see Lomax and Casy (1998) for a discussion), these research papers make no mention of the quality of data captured or the acceptability of the camera to the participants. Furthermore, they offer no help to a researcher battling with the myriad of ethical and consent issues to be considered when recording and storing an image of someone with dementia.

Pilot work was conducted with the primary aim of determining the feasibility and acceptability of using video to observe the non verbal communication of people with dementia. This aim was met by addressing the following five objectives:

1 Establish whether it is possible to observe and record the non verbal behaviour of people with dementia using a video camera.
2 Determine the quality of data captured by the camera.
3 Assess the acceptability of the presence of the camera to the participants.
4 *Highlight the particular ethical issues related to recording and storing an image of someone with dementia.*
5 Develop informed consent procedures for using video to observe non-verbal communication amongst people with dementia.

Methods

Communication amongst people with dementia was observed naturalistically by two researchers using both participant observation and a video camera. The views of participants with and without dementia were sought as to the acceptability of the camera and the quality of the data. Observations were analysed qualitatively.

The video recorded observations of interactions were conducted in three settings involving 12 older people with dementia. The majority of observation occurred in a dementia specific day centre in central Scotland, where 10 people with dementia who attended on a specific day of the week were observed interacting with each other and six members of staff. In addition, two individuals recognised as being skilled at communicating with people with dementia were videod having one to one interactions with someone with dementia they knew well. These interactions both took place in nursing homes in central Scotland. Participant observation was carried out in the day centre only.

Informed consent was obtained from significant others for all participants with dementia. Consent was also sought from the people with dementia themselves.

Findings

Non verbal communication can be observed both by participant observation and using a video camera.

Two researchers can independently identify the same non verbal behaviours of people with dementia. Behaviours observed included: gestures to amplify meaning, e.g. miming the buttons on a cardigan; gestures to replace words, e.g. circling hand about head to indicate memory loss; non verbal conventions of conversation, e.g. leaning in when listening; and making non verbal jokes, e.g. by pulling funny faces. The video recordings captured many of the same behaviours and revealed additional subtle details of non-verbal behaviour, missed in the participant observation.

Video can be used to capture detailed and representative information about non-verbal communication.

The quality of the data captured by the video camera was assessed in three ways. Comparison with the findings of the participant observation show that the video recorded observations capture the same kinds of behaviour and allow for more subtle, detailed behaviours to be identified. Review of the video by staff who had participated in the original interaction confirmed that the recordings were an accurate record of what had occurred. Review of the video by staff in the setting who were not present when the recording was made confirmed that the data was representative of the kinds of activities that happen in the setting.

The presence of the video camera is acceptable to the participants, particularly those with dementia.

Analysis of the videos showed that the participants without dementia were more aware of the camera and were observed to look at, or speak to, the camera more than those with dementia (unless their attention had been drawn specifically to it). All the participants with dementia said both before and during the recordings that they were happy to be video recorded. Many were interested in the camera and enjoyed looking at it and recording each other through it. When asked after the interaction if they had noticed the camera, responses indicated that they hadn't particularly, as would be expected from their observed lack of orientation to it whilst being recorded.

The participants without dementia reported more awareness of the camera, but all said that this faded over time, reporting that they "just got on with it". None of the interaction partners without dementia felt that the camera impacted on their ability to interact.

Ethical Issues

Key ethical issues highlighted by the research include:
Obtaining informed consent for participation in the study.
Preserving the anonymity of the participants whose image is recorded on video.
Striking a balance between reminding the participants they are being observed and part of a study often enough so they can continue to give or refuse consent but not so often that it impacts on their experience at the day centre.
Using the recording for dissemination of findings.

Consent procedures

Consent was sought from the participants with dementia both formally and in an ongoing informal way. Formal consent was sought from 10 of the participants with varying success. Participants either gave reasonably informed consent, uninformed consent or uninformed disconsent. The two participants who said they didn't want to be part of the study when approached formally, both said that they were too frail to be of any use to us immediately the word "project" was mentioned. The ensuing discussion caused both the participants and the researcher discomfort, despite the fact that both participants happily agreed that the researchers could come back to the day centre, watch and join in what was going on. Given that all but two of these consent discussions were felt by the researchers to be either disempowering or meaningless, further consent was pursued in an ongoing, more informal way.

This was done by reminding the attendees they were part of a study when appropriate opportunities arose, involving them in watching each other's body language so they might get a feel for what the study was about, encouraging them to handle and record with the video camera, and eliciting the help of the participants without dementia in explaining what was going on and asking if it was OK to continue. The researchers also paid careful attention to both verbal and non verbal behaviour for indications of the participants willingness to be involved.

Discussion

This pilot work shows that it is possible to observe the non verbal communication of people with dementia and it is feasible to use a video recorder to capture this information. The quality of data obtained by the camera was good, as judged by several criterion and the presence of the camera was acceptable to all involved. The permanent nature of the interaction enables the identification and

interpretation of more subtle and complex non verbal behaviours, allowing more detailed analysis of the interactions.

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Appendix C

Hubbard, G., Cook, A., Tester, S, and Downs, M (2002) Beyond words: older people with dementia using and interpreting non-verbal behaviour. *Journal of Aging Studies.* 16: 155-167.

Beyond words
Older people with dementia using and interpreting nonverbal behaviour

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Abstract

This article addresses a gap in research on nonverbal communication and dementia. It presents findings from a study that explored ways in which older people with dementia used and interpreted nonverbal behaviour within the context of social interactions. Two researchers, using an ethnographic approach, jointly observed nonverbal communicative behaviours occurring in a day-care centre. The findings show that older people with dementia used nonverbal behaviour in meaningful ways for others to interpret, and as a way of self-communication; and that they actively interpreted others' nonverbal behaviour. In specific situations, these people acted in the context of shared meanings, possessed a 'self', and took on the 'role' of others. This approach has implications for understanding the social experience of dementia and for the ways that care is organised. The role of nonverbal behaviour offers potential for carers to preserve older people's self-identity and improve their quality of life and care. © 2002 Elsevier Science Inc. All rights reserved.

1. Introduction

The number of older people with dementia in nursing and residential homes in Britain is rising (Melzer, McWilliams, Brayne, Johnson, & Bond, 1999; Spicker & Gordon, 1997). The quality of life and care of this population is an area of growing concern within social care research, policy, and practice. Whilst there has been a tendency to focus on this group of people's physical and functional ability (Bowling, 1998; Farquhar, 1995; Fitzpatrick et al.,

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1992; MacKeigan & Pathak, 1992; Turpie, Strang, Darzin, & Guyatt, 1997), there is increasing recognition that dementia is an experience to be lived meaningfully and not only a problem of disease (Kitwood, 1997a, 1997b). The impetus to move beyond health and embrace wider understandings of the experience of dementia is twofold. First, the concepts of person-centred care and personhood have shattered the notion that the person with dementia has no sense of self, personality, thought, or feeling (Downs, 1997; Kitwood, 1997a, 1997b). Second, there have been attempts to broaden definitions of quality of life and care to include social, psychological, emotional, interpersonal, relational, cultural, spiritual, and environmental dimensions (Birren, Lubben, Cichowlas Rowe, & Deutchman, 1991; Lawton, 1991; Logsdon & Albert, 1999; Whitehouse, 1999). At the same time, the basic values of privacy, dignity, independence, choice, rights, and fulfilment, have been used for evaluating quality of life in care homes (Department of Health and Social Services Inspectorate [DOH/SSI], 1989, 1990, 1993; Kellaher, 1998; Raynes, 1999; Residential Forum, 1996). The culmination of these developments is a move towards an exploration of the social experience of dementia as opposed to medical understandings of the disease.

Within this social framework for understanding the experience of dementia, there has been a growth of research focusing on communication. Research shows that older people with severe cognitive impairment are more likely to be disengaged and isolated than their less cognitively impaired counterparts in all settings (Armstrong-Esther & Brown, 1986; Chen, Ryden, Feldt, & Savik, 2000; Nolan, Grant, & Nolan, 1995). Ekman, Norberg, Viitanen, and Winblad (1991), for example, compared nurses' time spent with patients with severe dementia and no dementia on a hospital geriatric ward. They found that nurses spent less time interacting with patients with severe dementia because of their perceived inability to communicate. Indeed, there has been plenty of research documenting the specific language deficits that people with dementia may experience, including: vague and empty speech, diminished vocabulary, faulty linguistic reasoning, changes in word association patterns, and disordered discourse (Bourgeois, 1991; Whitehouse, 1999; Whitehouse et al., 1997). The extent of these communication problems is reflected in the finding that nearly half of nursing home residents never talk to their roommates due to hearing and speech impediments (Kovach & Robinson, 1996). These verbal communicative impairments, especially when combined with sensory impairments, are likely to make it difficult for many older people with dementia to engage socially.

Given the verbal communicative difficulties described, there is developing interest in the role of nonverbal communication in the lives of people with dementia. It is estimated that nonverbal behaviour comprises 55–97% of the message communicated in adult interaction (Gross, 1990; Hargie, Saunders, & Dickson, 1981) and includes body movement, facial expression, touch, physical appearance, personal space, and vocal communication such as pitch, intonation, and speech rate (see Argyle, 1988, for an overview). Existing research on nonverbal communication within the field of dementia however, tends to be limited to the investigation of two channels: touch and facial expression, and does not include an exploration of the ways in which older people with dementia interpret and define nonverbal behaviour within specific social contexts.

Previous research on touch has tended to focus almost exclusively on the touch of the professional caregiver and the response of the older person being touched (McCann & McKenna, 1993; Moore & Gilbert, 1995; Rundqvist & Severinsson, 1999). A typology of touch has emerged within this body of work including two types of touch: 'instrumental' touch is bodily contact that is employed for a purposeful task, and 'expressive' touch is that which is spontaneous and affective (McCann & McKenna, 1993; Routasalo, 1996). Parts of the body where professional carers touch the older person have also been identified (Watson, 1975). There is, however, a notable absence from the literature of any attempt to understand the ways in which older people with dementia touch.

Existing research on facial expression tends to fall within two categories. Either researchers have studied the extent to which older people with dementia use facial expression (Asplund, Jansson, & Norberg, 1995; Jansson, Norberg, Sandman, Athlin, & Asplund, 1992; Magai, Cohen, Gomberg, Malatesta, & Culver, 1996; Smith, 1995), or have explored the ways in which professional carers impute meaning to the older person's feelings, and understand their needs and desires by observing facial expression (Asplund et al., 1995; Athlin, Norberg, Axelsson, Moller, & Nordstrom, 1989; Hallberg & Norberg, 1990; Jansson et al., 1992). Again however, absent from this body of research is evidence reporting older people themselves interpreting and defining the meaning of facial expression.

Despite the paucity of research on the nature and meaning of nonverbal communication amongst people with dementia, the significance of nonverbal communication for measuring quality of life and care of older people with dementia has been recognised. A number of instruments have been developed, which focus on nonverbal behaviour to measure aspects of quality of life. In the UK, Perrin (1997) designed the Positive Response Schedule, which is used by observers to code 'micro behaviours' such as smiles, nods, gestures, and eye contact. This schedule was used to evaluate the impact on well-being of a range of different sensorimotor occupations such as music, massage, and flower arranging with older people with severe dementia in a residential setting. In North America, Lawton, Van Haitsma, and Klapper (1996) developed the Affect Rating Scale, which measures positive affect (pleasure, interest, contentment) and negative affect (sadness, worry/anxiety, and anger) by direct observation of facial expression, body movement, and other nonverbal cues of older people with, and without, Alzheimer's disease. Magai et al. (1996) coded movement changes in facial expression of residents in a nursing home who were experiencing mid to later stages of dementia as a way of studying emotional expression and thereby a person's likes and dislikes.

Review of relevant literature reveals that understandings of nonverbal communication and dementia are mainly limited to either developing typologies of nonverbal behaviour as the disease progresses or are explored from the perspectives of professional and family caregivers. There is an absence of research that explores the ways in which the older person with dementia uses, interprets, and defines nonverbal behaviour within specific social contexts and within specific situations. This article will address this gap by analysing findings from a qualitative study of the nonverbal communication of older people with dementia attending a day-care centre. The aim of the investigation was to explore the ways in which older people with dementia use and actively interpret nonverbal behaviour within the context of social interactions among older people, their professional caregivers, and the researchers at a day-

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nonverbal behaviour in the context of the day-care centre and in specific situations. At the end of each observation session, the researchers compared their observations of nonverbal communication and their interpretations of the meaning of these behaviours. They then examined their interpretations in relation to the older people's self-reported interpretations and any staff response to, or interpretation of, these behaviours. A qualitative approach to analysis was adopted. Each set of fieldnotes was reiteratively examined for themes that were evident in one or more of the nonverbal communicative behaviours that had been observed. Most of the observed nonverbal behaviour was analysed in relation to the ways in which the older people with dementia interacted with each other, their carers, and with the researchers, and the ways in which they interpreted each other's nonverbal behaviours. It is the relationships between people that provide the substance of this group of older people's communicative worlds.

3. Findings

The observations show that the nonverbal behaviour used by older people with dementia in a day-care centre was employed in meaningful ways. The researchers observed older people with dementia acting in situations suggesting that they were interpreting other people's nonverbal behaviour and giving meaning to specific nonverbal actions of others. Their social action suggests that they possessed a sense of 'self' and took on the 'role' of others in the context of shared meanings.

Some of the older people with dementia used physical contact and proximity to initiate, enhance, and maintain spoken conversation. One of the reasons why physical contact was important for some older people with dementia was that they had hearing impairments or had difficulty speaking out loud and so needed to be physically close to the person they were talking with. Touch and body posture were used by some of the older people with dementia to signal to other people that they wanted to engage in conservation. For example, Nicola, who has a significant hearing impairment, required people to sit close by if she was to converse with them. Nicola was observed using physical contact to initiate a conversation. She touched one of the researchers by the arm and told her to come in closer so that she could talk with her. On another occasion, Nicola affectionately pulled a female care worker's long hair to gain her attention. When Nicola was asked why she had pulled the carer's hair, she replied, 'to get her attention, of course'. Other nonverbal behaviours were used by Nicola to enhance spoken conversation. She was observed leaning forward and presenting her best ear when she was engaged in conversation with a carer. She was very tactile, sitting close enough for her arm to touch the carer's arm, and occasionally touched the carer's hand and lower arm. Other older people with dementia at the day centre also used nonverbal behaviour to facilitate communication. Maria would occasionally touch Timothy's arm whilst engaged in a conversation, and when a researcher sat down next to Timothy he orientated his body position so that they could talk. These examples suggest that the older people used nonverbal communication for practical reasons but they also show that they were acting in the context of shared meanings as others interpreted their behaviour in ways intended.

Older people were observed using nonverbal behaviour to amplify the meaning of verbal communication. Several older people were curious about what the researchers wrote down in their notepads when they made fieldnotes during some of the periods of observation. Nicola leaned over and asked one of the researchers what she was writing down in her notepad and said that she needed a spy glass to read what was written, whilst miming the use of a spy glass with her hand and eye. Another older person also demonstrated with his hands how a leather strap went over the shoulder, showed the length of a bar with two fingers, mimed buttons down the front of this jumper, and mimed hammering whilst at the same time slowly explaining through the spoken voice. Their nonverbal behaviour in the context of what was also being verbally communicated suggests that they carried expectations about the meanings of the actions and were acting in the context of shared meanings.

The use of nonverbal behaviour was one of the ways in which older people remained part of the communicative world when they were not actually engaged in a conversation. Since verbal communication was difficult for many of the older people due to their physical and mental frailty, many of them sought to interact socially and communicate meaning through touch. Nicola took one of the researcher's hands whilst the two sat together watching the others in the group. On another occasion, she placed her hand on the researcher's lap and pointed to something wrong with her hand. This led to a short, one- or two-sentence discussion with the other older women in the group about Nicola's hand and resulted in all members of the group putting their hands out to be felt and compared for softness. One of the professional care staff massaged the older women's hands and put on nail varnish. This physical contact was the main form of social interaction but was occasionally interspersed with snippets of verbal communication as the group of older women admired their varnished nails. Affective touch was used by some of the older people with dementia for reassurance. For example, one of the older women was disorientated and did not know where she was. When the researcher went with her for a walk around the courtyard, the older woman took her hand and held it until she reorientated herself and joined the rest of the group.

Some of the frail older people used nonverbal behaviour to compensate for their loss of verbal communicative abilities. Their nonverbal behaviour became the main way in which they remained part of the communicative worlds of the day centre. Steven managed to retain a strong presence in the group and maintained social contact with others by portraying humorous facial expressions. He would widen his eyes, grin, and wriggle his ears. He also would pose with his arm and hand limp. The researchers believed that Steven developed this strategy as a ploy to cover up his inability to hold a conversation. Although he appeared to understand a person's questions, and would often reply with a one-word answer, he rarely spoke in full structured sentences. Instead, he would answer direct questions with short, two-word answers and he would pull a funny face. His use of facial expression to communicate humour was thus his unique way of remaining an active participant in the communicative world. Steven's actions suggest that he purposefully developed nonverbal behaviours to make others laugh whilst the intention was to disguise his lack of verbal communicative ability. Steven's actions imply an awareness of 'self' because he understood the meanings of his nonverbal behaviours. The fact that the other older people interpreted his nonverbal behaviours

as funny suggests that they took on the 'role' of Steven as part of the process of interpreting the meaning of his actions.

This notion of meaning and intention of nonverbal behaviour was also observed in different situations. An older person may use nonverbal communication such as body posture to intimate that they are actively listening to others engaged in a conversation whilst not being part of the conversation themselves. Again, the use of nonverbal behaviour was used as a way of being part of the communicative world without verbal utterances. Steven appeared to be following a conversation held between two older people. He leant slightly forward in his chair towards them and slightly cocked his head, yet he made no effort to join in the conversation, looked directly ahead into open space, and was not invited to join in the discussion. It was doubtful that he could hear what the two older people were saying as he was sitting slightly to the right of them and they were both talking quietly and directly to each other. It was only when they directed a question specifically to him that he would respond with one- or two-word answers. Steven's actions suggest that he was aware of the meaning of particular body postures and adopted them to give the impression that he was actively engaged in the conversation whilst his intention may have been to disguise his inability to communicate verbally. His projection of 'self' as an active listener suggests that he was aware of how his actions would be interpreted by others and that he was acting in the context of shared meaning. What is not clear is whether Steven was consciously using nonverbal behaviours to disguise his inability to converse.

Some of the older people with dementia at the day centre used physical contact with inanimate objects to convey meaning to their 'self'. That is, they were the object of their own actions. James gently and continuously rubbed the top of his walking stick and, on other occasions, he would lightly rub the chair arm. When asked why he touched his walking stick he replied that he wished to be reminded that it was there because he would not be able to walk without it. Maintaining physical contact with an inanimate object was thus his way of reminding himself and being reassured that he had the walking stick close at hand. Older people with dementia were also observed using objects to convey meaning (either consciously or unconsciously) to others. James began to gently pat his catheter bag on his thigh. One of the researchers assumed that this was in response to the bag being full and informed one of the professional carers. The carer came across and gestured to James to come with her and pointed to his thigh at the same time as pointing in the direction of the toilet. As James got up from his chair to follow the carer he smiled to the researcher and laughed saying that he needed to go to the bathroom. Maria placed her walking stick between her legs and put both hands on it as if to indicate to the professional carers that she wished to get up. It was evident that she also wished to go to the toilet.

These incidents suggest that nonverbal communication was employed as a way of conveying meaning to the professional carers and were adopted in the context of assumed shared meanings. Saying certain things out loud, such as wanting to use the toilet, may have caused embarrassment to the rest of the group or to the older people themselves. James and Maria may also have perceived asking to go to the toilet as demeaning and so used nonverbal behaviour to indicate their need instead. Other older people with dementia were also observed using nonverbal communication in preference to the spoken word

within specific situations. For instance, Timothy chose to use nonverbal behaviour rather than actually say what he wanted to communicate. Timothy was aware that he had dementia but he chose to indicate his disability nonverbally. He was very conversant and talked at length about a range of issues to the other older people at the day centre and to the researchers. He was explaining to one of the researchers why he attended the day centre. Rather than saying that he had a cognitive impairment, he lifted his finger above his head and moved it around in circular movements. The researcher asked him what this gesture meant and Timothy just laughed.

Professional care staff may also interact with frail older people using nonverbal forms of communication in preference to the spoken word. The use of nonverbal communication enables older people who may have difficulty engaging in conversation to join in with the group activities and socially interact. During one sunny morning at the day centre, the older people sat outside. The professional carers used the task of helping the older people to take off their coats and handing out sun hats as opportunities for physical humour. One of the professional carers dragged Loraine's coat off her with Loraine pretending to wrestle it back, both laughing. Mary followed suit, pulling another older person's coat off. The sun hats were thrown about and many of the older people and their professional carers attempted to throw the hats onto each other's heads. Some of the older people placed two hats on top of their heads to the amusement of others. The use of a water pistol was a further example of using nonverbal behaviour to socially interact. Loraine squirted the others with water amongst much hilarity. Larking about was thus one of the ways in which the older people and their professional carers at the day centre socially interacted. Loraine, in particular, used this nonverbal form of communication. Loraine would convert her taking of medicinal pills into a game. Mary popped the pills into Loraine's mouth but Loraine refused to swallow. Mary then poured water into her mouth and Loraine pretended to swallow, meanwhile winking at the researcher and indicating that the pills were in her hand. Both Mary and Loraine laughed and others joined in laughing as Mary pretended to scold Loraine for refusing to take her pills. In these situations, the meaning of nonverbal behaviour was interpreted within the contexts of games and play-acting. This game between Mary and Loraine suggests that they were taking on the 'role' of each other as they interpreted each other's behaviour.

Researchers also interpreted older people's facial expressions in the context of social interaction. When Nicola was not engaged in conversation, her facial expression would change from appearing animated and attentive to one of apparent vacancy. Her face would drop, her eyes would stare ahead, and her face would remain motionless. Some of the professional care staff believed that this was an indication of Nicola becoming bored. The researchers, on the other hand, interpreted Nicola's facial expressions slightly differently. They believed that Nicola continuously fought to remain part of the communicative world. This struggle to communicate was manifested in changes in facial expression. When Nicola was successfully interacting with others, her face would appear animated. However, when she was unable to communicate she appeared withdrawn and vacant. It was not that she got bored, it was rather that her struggle to communicate sometimes failed. This example points to the ways in which different people may attach different meanings to the same nonverbal behaviour.

4. Discussion

This article shows that older people with dementia used nonverbal behaviour in meaningful ways for others to define and interpret, used nonverbal behaviour as a way of communicating to themselves, and actively interpreted the nonverbal behaviour of others. Within an interpretative symbolic interactionist perspective these findings suggest that this group of older people with dementia acted in the context of shared meanings and expectations, possessed a 'self', and took on the 'role' of others. The findings show that some of the older people's nonverbal behaviour had multiple meanings. For example, one of the research participant's nonverbal behaviour gave the impression to others that he was engaged in a conversation, but the researchers interpreted his behaviour as disguising his inability to converse. The findings also show that older people with dementia use and interpret nonverbal behaviour in specific social contexts and within specific situations. The social context was the day centre and the specific situations arose within the social interactions among the older people, their professional caregivers, the researchers, and other older people attending the day centre.

This approach to observing and analysing nonverbal behaviour has implications for understanding the social experience of dementia. There is considerable debate over the extent to which older people with dementia remain active, creative, and meaning endowing agents possessing a sense of 'self' (Cohen & Eisdorfer, 1996; Kitwood, 1997a, 1997b). The findings reported in this article suggest that despite verbal communicative deficits and cognitive impairments, older people with dementia use and interpret nonverbal behaviour in their determination, and struggle to remain part of the communicative world. Arenas of care in which the interpersonal relationships of older people are encouraged through nonverbal forms of communication may provide pathways in which older people with dementia maintain a sense of personhood. Encouraging nonverbal communication may offset a spiral of decline because it is one of the ways that older people with dementia meaningfully engage and preserve a sense of 'self'. The findings suggest that older people with dementia develop their own unique ways of utilising nonverbal behaviours to express their personality and communicate meaning. Through acts of resistance against the detrimental effects of dementia on their verbal abilities by utilising nonverbal communicative skills, older people with dementia can remain part of the communicative world.

These findings also have implications for the ways in which care is organised. Nonverbal communication, just like any other form of communication, may be conceived as arising within three facets of context (Gubrium, 1995). Gubrium's conceptualisation of the act of story-telling may be adapted and applied to acts of nonverbal forms of communication. One of the three facets of context that Gubrium highlights and that is pertinent to this study is the 'local culture' within which the act of nonverbal communication takes place. This may include for instance, an older person's friendship circle, the residential, or day-care centre setting, which all serve to frame the social experiences of the older people. The local culture became the subject of this investigation, and is one context that influences an older person's quality of life and care since it is an arena in which interpersonal relationships can either flourish or wither. The findings reported in this article suggest that care settings may

contribute towards developing care practices that utilise nonverbal forms of communication and thus enhance interpersonal relationships between older people themselves, and with their care staff. In the day centre, professional carers were observed conducting social activities that did not rely on verbal communication and were observed interpreting the nonverbal behaviours of the older people with dementia. The people at the day centre acted in contexts of shared meaning where they took on the 'role' of others as part of the process of interpreting nonverbal behaviours. In this sense, it provided an arena in which older people with dementia were able to socially interact and communicate through nonverbal channels. It was a social context in which the older people with dementia were engaged in situations where they were meaning-endowing agents, using, interpreting, and defining nonverbal behaviour.

Rather than relying on verbal expressiveness, care practitioners need to be developing ways of both interpreting and encouraging the use of this form of communication. These findings show that nonverbal communication has four important advantages. First, it provides a way of understanding what older people with dementia are thinking and feeling as their dementia begins to inhibit their verbal communicative abilities. Second, strategies relying on nonverbal behaviour have the potential to be inclusive, since all older people, including those who may have difficulty communicating verbally, may participate. Third, it widens the scope, and opportunities, for older people to develop interpersonal relationships because there is less reliance on verbal communication. Fourth, it enables older people to communicate meaning nonverbally, thus avoiding demeaning themselves or embarrassing others as a consequence of saying things out loud.

Inadvertently, caregivers, relatives, and wider social and cultural influences can impede an older person's attempts to communicate through failing to recognise the nonverbal communicative skills that the person with dementia still possesses. Kitwood (1997a, 1997b) believes that much of the social interaction and communication between older people with dementia and their caregivers can be described as 'malignant social psychology'. This is where, for example, older people with dementia are disempowered, ignored, and disparaged. In contrast, Kitwood (1997b, p. 94) calls for person-centred care practices whereby personhood is maintained through social interaction and communication that is 'according to each individual's needs, personality, and abilities'. On a more optimistic note, it is becoming increasingly acknowledged that good dementia care is synonymous with interpersonal relationships between older people with dementia and carers that rely more on emotional, sensitive, and empathetic interactions rather than on verbal expressiveness (Bond, 1999; Russell, 1996). The findings reported in this article suggest that part of the process of moving towards person-centred care is embracing the role of nonverbal behaviour in older people's communicative worlds and endorsing these communicative skills that older people with dementia still possess. Acknowledging the range of nonverbal communicative abilities of older people with dementia, rather than concentrating only on a decline in verbal communicative skills, is part of the process of the 'emergence of the person in dementia research' (Downs, 1997). Recognising and working with nonverbal communication may be one of the ways in which caregivers can contribute towards the preservation of self-identity and personae, and thus contribute towards improving quality of life and care.

Acknowledgments

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Appendix D

Ailsa Cook and Gill Hubbard (2000) Beyond Words: The use of nonverbal communication in interactions amongst people with dementia. *Pathways, Communication and Dementia Newsletter* Number 7. Dementia Services Development Centre.

Hearing the Voice of People with Dementia

Beyond words:

The use of nonverbal communication in interactions amongst people with dementia   *by Ailsa Cook & Gill Hubbard*

Earlier this year Gill and I embarked on a small research project to see if it was possible for researchers to watch and interpret the nonverbal communication of people with dementia. We both spent time in a day centre in central Scotland, joining in the activities and observing what was going on. We asked the attenders with dementia if they could tell us what certain nonverbal behaviours meant and paid close attention to the ways in which staff responded to these nonverbal behaviours. At the end of each observation session in the day centre we would write up detailed notes of what we had seen and would compare interpretations of the nonverbal behaviours we had both observed. We also compared our interpretations of behaviours with the interpretations offered by the people with dementia themselves and the responses of the staff.

The purpose of the project had been to see if it was possible for researchers to observe and interpret nonverbal behaviour, and indeed we found that it was. However we also became very interested in the role of nonverbal communication in interactions between people with dementia. This article describes some of the ways we observed people's experiences of dementia in relation to their use of nonverbal communication in interactions.

Reinforcing the meaning of what is being said

We often observed the attenders' use of nonverbal behaviours to reinforce what they were saying. For example, Ted mimed buttons whilst he was talking about a cardigan, and showed the researcher how long the piece of wood he was referring to was using two fingers. Nicola made her thumb and finger into a circle and put it up to her eye whilst talking about needing an eyeglass.

Getting people's attention

Several of the attenders were seen using nonverbal behaviours to get the attention of those around them. Nicola affectionately pulled a member of staff's hair while she was talking to someone next to her to get the staff member to talk to her. Ted tapped the bench he was sitting on to encourage one of the researchers to sit next to him.

Showing you are listening

The attenders used nonverbal behaviours to show that they were listening in a range of ways. We watched an interaction between Sam, Ted and Mary. Both Sam and Ted had their bodies turned towards Mary in the middle and had their ears cocked towards her, meanwhile Mary frequently tapped Ted on the arm whilst they chatted.

Making a joke

Nonverbal humour played a big part in many of the interactions we observed at the day centre. For example Sam frequently pulled funny faces to make a joke, and put on two sun hats at once to the amusement of everyone around him. Lena had a tug of war with a care worker, pretending she didn't want to give him her coat to hang up, and made a big joke of refusing to take her pills. The staff often played an important role in encouraging this physical humour.

Offering comfort

Touch in particular was used by everyone at the day centre to offer comfort. Care staff would sit holding hands with the person whilst chatting and would often take their hand or arm whilst walking. Indeed when I went for a walk with Jenny who was slightly agitated, she immediately took my hand and hung onto it until she was more orientated and happy. This was despite only having met me the same morning.

This picture comes in from RCN VIDEO *When Heart Wants To Remember.*

When things are best left unsaid

We observed the attenders using nonverbal behaviours to avoid speaking about sensitive topics out loud. In particular people very rarely asked for help to go to the toilet. Mary for instance, moved to the edge of the chair and placed her walking stick between her legs to indicate that she wished help to get up. Jimmy rubbed his leg where his bulging catheter bag was instead of asking for it to be emptied. Staff were very sensitive to these cues and responded by gesturing or asking in a whisper if the person was wanting to go to the toilet.

Our research shows that people's use of nonverbal communication is very similar to the ways we all use nonverbal communication in our lives. The difference for the people with dementia we observed in this day centre was that many of the meanings conveyed would not have been communicated without nonverbal communication. For example, Jenny responded much better to the squeeze of her hand than she did to my attempts to explain to her in words where she was, and Sam made his presence very much felt at the day centre by his faces and humorous antics, despite rarely uttering a word. Our findings show that people with dementia are very good at using nonverbal communication to convey a wide range of meanings. The challenge for carers is to provide a supportive setting for this, by paying close attention to *all* of the person's ways of communicating and reflecting on how they too might communicate *beyond words.*

Gill Hubbard is the Research Fellow on an ESRC funded project with Sue Tester (in the Department of Applied Social Science at Stirling University) and Murna Downs (of Bradford Dementia Group) looking at the quality of life of older people in nursing homes. Ailsa Cook is a PhD student, also in the Department of Applied Social Science at Stirling. She is looking at how

Appendix E

E (i) Information sheet for older residents asked for written informed consent.

E (ii) Consent form for older residents asked for written informed consent

E (iii) Information sheet for older residents not asked for written informed consent

E (i)

Observing Older People's Communication

A Research Project by
Ailsa Cook

Department of Applied Social Science,
University of Stirling

INFORMATION SHEET FOR RESIDENTS

When you decide if you are willing to be part of the study, please note that:

- You are free to change your mind at any time

- You do not have to give a reason for your decision

- Your decision will not affect your care in ~~~~~~ in any way, now or in the future

If you are willing to be part of the study, please sign the consent form. Once you have completed the form you may return it to me in the envelope provided or leave it at the office of ~~~~~~

If you have any questions about this study please do get in touch with me. I will be very happy to talk to you on the phone or come to ~~~~~~ and talk to you in person.

Ailsa Cook
Department of Applied Social Science,
University of Stirling,
Stirling, FK9 4LA
☎: 0131 447 8269 or 01786 466307

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Observing Older People's Communication

A Research Project by Ailsa Cook

Department of Applied Social Science,
University of Stirling

CONSENT FORM

Ailsa Cook
Department of Applied Social Science,
University of Stirling,
Stirling, FK9 4LA
☎: 0131 447 8269 or 01786 466307

Please return this copy to Ailsa. You may leave it for her at the office at   or send it to her at the Department of Applied Social Science

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INNOVATION and EXCELLENCE

Observing Older People's Communication

A Research Project by Ailsa Cook

Department of Applied Social Science,
University of Stirling

INFORMATION SHEET FOR RESIDENTS

If you agree to take part in the study, please remember that:

◆ You are free to change your mind at any time

◆ You do not have to give a reason for your decision

◆ Your decision will not affect your care in ▓▓▓ in any way, now or in the future

If you have any questions about this study please do get in touch with me. I will be very happy to talk to you on the phone or come to ▓▓▓ and talk in person.

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Appendix F

Cook, A. (2003) Using Video to Include the experiences of people with dementia in research. *Research, Policy and Planning* **21** (2): 23-32.

Using Video to Include the Experiences of People with Dementia in Research

Ailsa Cook, Centre for Research on Families and Relationships, University of Edinburgh, Scotland

Abstract
There is a need to develop more inclusive approaches to researching the experiences of older people with dementia if research is to counter the marginalisation and exclusion they face. This paper outlines findings from a study using video to research the communicative experiences of older people with dementia. Video was found to be a useful tool, enabling the inclusion of this group's experiences in research and their involvement in the research process. The implications of these findings for video research and the involvement of people with dementia in research are discussed.

Introduction

The aim of this paper is to examine critically the usefulness of video as a research tool for both researching the experiences of older people with dementia in a residential care home and for facilitating their involvement in the research process. The use of video as a research tool is reviewed and the methods used to collect the data for the study outlined. Findings from the study are presented concerning the usefulness of video for researching the experiences of people with dementia and involving them in the research process. Finally the paper reflects on the meanings of involvement for both the person with dementia and the researcher.

Involving People with Dementia in Research

The marginalised status of older people with dementia in society has consequences for researchers wishing to study this population (Wilkinson, 2002). Seemingly objective research findings and representations can lead to the 'othering' of people with dementia, exacerbating their marginalisation and disempowerment (Fine, 1994). There is, however, a growing body of research working to counter these processes, seeking to understand the perspectives and experiences of people with dementia themselves (Clarke and Keady, 2002). In particular, the perspectives and experiences of people with dementia have been sought in relation to the services they receive (Allan, 2001; Barnett, 2000; Dabbs, 1999; Pratt, 2002; Reid et al, 2001); and their experiences of dementia (Cheston and Bender, 2000; Sabat 2001; Snyder, 1999). This research has tended to focus on people with moderate and mild dementia, and little attention has been paid to non-verbal aspects of the experience of people with dementia.

This body of research, however, constitutes only a small step towards addressing the exclusion and marginalisation of people with dementia. Writing from the field of disability, Oliver (1993) argues that for research to foster positive change in the status of marginalised populations, researchers need to work in 'joint enterprise' with marginalised people. Emancipatory and participatory approaches to research, widely used in the fields of disability and feminism, provide models for a new kind of dementia research which allows people with dementia themselves to determine research priorities and methods (e.g. Millen, 1997; Walmsley, 2001). In this way, people with dementia may actively participate in moves to challenge their 'othering' and marginalisation.

These approaches to research have started to permeate the field of dementia research (Corner, 2002). Where once people with dementia were treated exclusively as the objects of research, now their consent is routinely sought for participation (Dewing, 2002; Hubbard et al, 2002). Moves to a more participatory, or even emancipatory approach to research with people with dementia, however are slow. Expertise in consulting with and working with people with dementia is growing (see Wilkinson, 2002 for a collection of chapters), however very few people with dementia are actively involved in shaping research. Those that have been involved have highlighted the many benefits to them, particularly in terms of increased self-worth, confidence and optimism (McKillop, 2002; Robinson, 2002). However, many barriers still exist to involving people with more advanced dementia and those who are not familiar with research practices. There is an urgent need to develop new methodologies to allow the inclusion of all people with dementia in research.

Video as a Research Tool

Video is a relatively under-used tool in social science research (Prosser, 1998). Video recordings of social life allow non-verbal aspects of experience to be captured and create a permanent record of the experience that may be subjected to micro-level analysis time and time again (Rosenstein, 2002). Furthermore, video enables those involved in the interaction recorded to reflect and comment on their behaviour (Caris-Verhallen et al, 2000: Sanders and Dabbs, 1992). In the field of dementia, video has been used successfully in both these ways to examine the responses of people with very advanced dementia and the perspectives of staff during caring interactions (Athlin et al, 1990; Kihlgren et al, 1996; Norberg et al, 1986; Phillips and Van Ort, 1993).

A key issue identified by many researchers who have used video to examine social life is the extent to which the recording is a true and representative depiction of 'real life' (Prosser, 1998). The potential distorting influence of the video camera on the behaviour of the research participants has been widely reported (Heacock et al, 1996; Lomax and Casey 1998; Rosenstein, 2002). Furthermore, the influence of the person using the camera on the data collected has been highlighted (Roberts et al, 1996; Rosenstein, 2002). Thus, the resulting recording can be seen to be both a social and technical construction. Post-modern and ethnographic approaches to research, however, question the extent to which a true and representative depiction of 'real life' is possible in any research (Denzin and Lincoln, 1994). These approaches embrace the influence of subjective aspects of the research relationship and situation on the data collected, and reflect on this in their analysis (e.g. Agar, 1996; Hockey, 1992; Sanger, 1996). In this context, the distorting influence of the video camera becomes merely one more aspect of the research situation to reflect on. Indeed Lomax and Casey (1998) demonstrate the possibilities for using the video recorded data itself to reflect on the influence of the camera in the construction of the research data.

Video and Involving People with Dementia in Research

The ubiquity of video in society makes it an ideal tool for involving people in research who are unfamiliar with traditional social science methods. Video has been used to disseminate the findings of a participatory project involving older women (Warren and Maltby, 2002) and as a medium for older people with dementia to document their life stories (Rose, 2000). Furthermore, the use of video enables researchers to reflect critically on the research process, which is essential to the development of new inclusive methodologies for people with dementia. In the field of midwifery, Lomax and Casey (1998) highlighted new mothers' perceptions of the video recordings as being the research proper, and revealed the ways in which they used the camera to differentiate what they considered to be midwifery business from social aspects of the visit. There has, however, been no critical reflection on the use of video in research in the field of dementia. Research from a nursing perspective has highlighted the ethical issues of preserving anonymity and consent (Heacock, 1996; Latvala et al, 2000; Roberts et al, 1996); however, so far, these issues have been ignored by dementia researchers using video.

The following sections will outline the use of video in this study to research the communicative experiences of older people with dementia. The success of this approach in both gathering data and in enabling the inclusion of the participants in the research will be considered. The implications of this for both video as a method and the inclusion of people with dementia in research will be discussed.

Research Aims and Design

The research presented in this paper forms part of a PhD study, examining the communicative experiences of older people with dementia in a residential care setting. The ethnographic methods of participant observation and informal interviewing were used to gather data in one residential care home over the space of six months. Both pen and paper and a video camera were used to record the residents' experiences, and the video recordings were played back to the participants to

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of the residents with dementia faced trying to understand the research. In the case of Maria, however, the special nature of being 'put in the machine' made it worth the struggle.

The increased understanding and awareness of the research fostered by the use of the video camera helped in the negotiation of ongoing consent with the residents. Not only was the camera meaningful to the residents, but it also provided a physical prompt, reminding them they were part of the research. This enabled more meaningful ongoing consent to be negotiated, residents changed their minds from day to day and even during recordings as to their willingness to be involved, as the following clip shows:

> Two residents, Elsie and Ginny, had been chatting together for some time when I asked if I could record them. They both agreed and I had been standing directly in front of them recording for five minutes before Elsie remarked to Ginny...
>
> E: this girl's standing here with that stupid..., will she no sit down? There's a seat there.
> A: I can't see you if I'm sat down, Elsie.
> G: She can't see if she sits down, she wants to take a photograph of you.
> *Elsie puts her head down and shakes it*
> G: *(looks at Elsie)* No?
> A: Would you rather I stopped?
> G: I think so.
> A: OK *(and I turn off the camera)*

Although use of the video camera encouraged residents to engage in the research and made the research process more meaningful, the camera did not overcome residents' difficulties in understanding the research aims. Analysis of the residents' responses to the video revealed that they reached many different understandings of the research, not all of them coinciding with mine. A common misinterpretation of the research was that it was about the residents' life stories, as the following clip shows.

> Whilst recording three residents chatting in the foyer, one of them, Jean, calls out to Ella who is passing...

> Jean: Where you going?
> Ella: I dinae ken (laughs). I'm walking but I didnae ken where I'm going
> J: Tell this young lady the story of your life.
> E: The story of my life (looks questioningly at Jean) I've nae life, I've nae life, I've been working too hard!
> (Ella laughs bitterly and sits down. Jean turns to me and says)
> J: ask Ella a question, like where she used to live.
> Researcher: So where did you used to live Ella?

This clip shows Jean clearly involved in the research, however operating with a very different conception of the project to my own. In one sense, this misinterpretation has few consequences for the study: Jean's question generated interesting data. However, this recording is evidence that Jean's consent to participate in the study is misinformed, which is problematic for any research, not least that which seeks to avoid disempowering the research participants. The response of a resident with more advanced dementia, in the following clip highlights this problem more starkly still:

I approach three residents sat in the foyer and ask if they are willing to be video recorded, explaining that it's for my study at the university on older people's communication. They all agree, however the first thing recorded when the camera is turned on:

> Anne: What's it for, the paper?
> Jean: It's not for the paper, *(to the researcher, joking)* the News of the World is that where you're from?
> Researcher: It's for my project.
> A: What?
> R: My project
> J: *(to the researcher)* She doesn't ken what a project is.
> R: My university studies.
> A: I didn't know what you said *(looking at me)*
> R: Right *(pause)* you can watch the video when it's done.

Therefore Anne, although clearly engaged with the research, cannot be said to have given informed consent for participation, raising a question as to

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whether I should include this data in the research. This issue will be considered in more detail in the discussion section of the paper.

Involving Residents in Data Collection and Analysis

To involve the residents in the data collection and analysis of the findings, residents were encouraged to use the camera themselves and were shown the findings and asked to comment on them. Neither method proved very successful.

Many of the participants in the study readily handled the video camera and recorded with it, however none of the residents in the home were able to see through the viewfinder. This meant that they had no control over what was filmed, rendering them unable to contribute to the data collection process in this way. Residents were, however, able to be involved in determining the data collection in different ways. The video camera provided a physical frame to the research, which residents were able to manipulate, giving them control over the data collection process. Residents commonly responded to this frame by 'voting with their feet' moving in and out of the research as they chose. One resident in particular, however, acted as a director, calling people in and out of the frame of recording and ensuring she was seen in a good light:

> Two residents are sat in the lounge as I ask if I could record them chatting.
>
> Marg: You can get that big handsome fella in, (then calls out to the passing man) come over here and get your picture took! (Anne turns round to look as does Marg, who then sees Lena)
> M: Lena you going to get your picture taken?
> L: Eh? (as she slowly approaches)
> M: You can get a seat up here, (pointing to a chair) you can get a seat round that way, you're getting your picture taken.
> L: Am I?

It is important to note, however, that Marg's active role in the research had implications for Lena who, through Marg's actions unwittingly participated in the research without giving consent to be recorded

on this occasion.

Involving residents in the data analysis was also problematic. For the most part residents enjoyed watching the video recordings after they had been taken, however it was hard to elicit their perspectives on the research in this way. Residents were readily able to reflect on their experiences of being recorded and on the feel of the recordings. They were less able to answer specific questions about the communication in the recordings, particularly if they had forgotten being recorded. Playing the videos back immediately after the event helped in this regard, but was not always possible depending on the availability of an appropriate television. Instead, residents laughed at the recordings, commenting on their own and others' hair and clothes. Although this method was not successful in eliciting the perspectives of the residents on the research, these sessions did make the research more meaningful for the residents, thereby facilitating their involvement in the day-to-day data collection for the study.

Reflections

Meanings of involvement

The findings raise many questions about what it means to involve people with dementia in research. Analysis of the recordings show that, through the use of an inclusive methodology, residents with dementia were clearly engaged in the research and interpreted meaning from it. Despite all my best efforts, however, the residents' understandings of the research, and in particular of the broader research aims, did not always correspond with my own. In many cases residents clearly consented to research they did not understand. Given both the cognitive impairments experienced by people with dementia, and in general their lack of experience of being involved in research, this situation is inevitable, and poses a challenge for the future involvement of people with dementia in research.

Current conceptualisations of participatory and emancipatory approaches to research and medical and social science ethical guidelines all place participant informed consent at the centre of ethical research practice (Dewing, 2002). However, findings from the study highlight the incongruity of imposing such a cognitively driven and abstract conceptualisation of good practice on people with

dementia, going against all the principles of person-centred-care. In this study, restricting the research to involving only those who gave informed consent would not only have prevented the recording of the experiences of many people with more advanced dementia, but would have precluded their involvement in the research process, leaving the participants disempowered either way. This is not to deny the importance of informed consent in research, but merely to highlight the problems inherent in this approach and the need to find new ways of conceptualising research if, as a field, we are committed to the involvement of people with dementia.

Table 1. Meanings of involvement for the researcher and the research participant.

Nature of involvement	Meaning for Researcher	Meaning for Research Participant
Awareness that being researched	Avoids disempowerment and 'othering' of participants	Provides opportunity to show 'best side' to the camera
Understanding of research process and aims	Enables informed consent	Gives status and sense of satisfaction / achievement
Informed consent to research	Meet requirements of ethical committees	Provides opportunity to exercise choice and self-determination
Participation in data collection and analysis	Avoids disempowerment and othering	Provides opportunity to show 'best side' to the camera.

A first step to finding a new way of conceptualising research that might ethically and meaningfully include people with dementia is to examine the meanings of involvement to them. Analysis of the video recordings and field notes enabled interpretation of a number of meanings for the residents of being involved in research. These are summarised in Table 1, alongside the meanings for me, the researcher, in involving residents in the research. Comparison of the two columns highlights the abstract concerns of the researcher

on the left as opposed to the very personal concerns of the participants on the right. As a researcher, I was motivated by theoretical and ethical understandings of research and the requirement of research ethics committees; however, involvement afforded the older residents with dementia, choice, status and some determination in the ways in which they were represented. Indeed, this finding is supported by the experiences of James McKillop and Elaine Robertson, whose chapters on the benefits of being involved in research highlight the importance of value, respect and relationship with the researcher and made no mention of ethics or guidelines (McKillop, 2002; Robinson, 2002).

Discussion

The findings show that in the context of an appropriate methodology, video is a useful tool for involving people with dementia in research. The older residents with dementia in this study found the activity of being video recorded both meaningful and interesting. Furthermore, the presence of the video camera provided the residents with a physical reminder that they were being recorded and were part of research. Thus the use of video, as opposed to pen and paper participant observation, made the research process transparent, facilitating the residents' involvement. Access to more appropriate technology would have facilitated the residents' involvement further. Use of a video camera with a screen on the side, would have enabled at least some of the residents to see what they were recording, enabling them to play a more active role in the data collection. Furthermore, ready access to a television with a scart socket[1] would have enabled the videos to be played back to the participants immediately, making it easier for them to comment on the recordings.

These findings also have implications for the field of video research more generally. In this study, the socially and technically constructed nature of the recordings, so frequently highlighted as problematic (Heacock et al, 1996; Prosser, 1998; Rosenstein, 2002), became an advantage. The overt use of the camera in the context of an inclusive methodology served to remind the participants they were part of the research and enabled them to control the data collected.

Analysis of these recordings enabled reflection on both the extent to which the research processes were empowering and their influence on the data collected.

Finally the findings have implications for our understanding of what it means to include people with dementia in research. The use of the video camera provided a permanent record of both my successes and failures in including the residents with dementia in the research process. Analysis of this data reveals that being involved in research is a meaningful experience for the residents, and that these meanings were of a very different nature to those of the researcher. The challenge for researchers working in this area is to develop inclusive methodologies that embrace both sets of meanings. Video is clearly a useful research tool to this end.

1. A scart socket enables the video camera to be plugged into the back of the television, allowing the recording to be viewed on the television.

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Appendix G

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