

*Personal Experiences of
Dementia and Care: The Views of
People with Dementia and their
Relatives*

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ABSTRACT

This study examined the possibilities of empowering people of a range of severity of dementia, by eliciting accurate views and feelings from them about services and including them in service evaluation. The study was underpinned by a four tier empowerment framework, which incorporated issues relating to the individual, the organisation, the service user and society. An ethnographic approach to data collection and analysis was employed. Twenty-seven people with dementia from Jewish Care residential and day care settings were interviewed and their daily lives videotaped and observed and interviews conducted with next of kin. Efforts were made to empower and involve participants in the research process as far as possible. Triangulation of interview, video and observational data reveal that with appropriate methods and skills it is possible to elicit accurate information from people in various stages of dementia, and thereby involve them in service evaluation. A number of techniques for communication are highlighted. Findings also show that although relatives' views are frequently taken as proxy for those of people with dementia, they may lack knowledge about services and the perceptions of people with dementia. In residential care their views differed considerably to those of people with dementia, suggesting that is important to consult with the person with dementia themselves. The data suggest that the experience of dementia was disempowering for both people with dementia and their relatives. In addition, although day care services were perceived more positively, people with dementia were disempowered by a lack of influence, control, communication and social aspects of care in residential settings and relatives by a lack of support and information in the community. Although participants were of Jewish origin and from Jewish settings only, it is considered that the results are more widely applicable to other groups of people in other settings. A number of recommendations are made about creating a more empowering workforce and environment and a model of empowerment for dementia research and practice is outlined.

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INTRODUCTION

The importance of ‘Service User Empowerment,’ a central theme in this study, has been increasingly emphasised over the years. The extent to which this is being put into practice however, is open to question, especially so with regard to some mental health groups, including those affected by dementia. In the past there has been little research carried out which takes account of the views of this particularly vulnerable group of people (Proctor, 2001; Clare, 2003; Gilmour & Huntington, 2005). User perspectives on the experience of dementia and on services have mostly been solicited from family carers, rather than from people with dementia themselves (Adams & Manthorpe, 2003); however it has been suggested that they may lack information and insight about service users’ experiences (Kemp et al, 2002; Stalker, 1999). There are a number of reasons for omitting views of people with dementia, which include the belief they are unable to participate in identifying how they experience care services, and that it is not possible to elicit valid, reliable information from them, because of their cognitive impairment (Corner, 2002). Because of their memory and communication problems, society has tended to perceive people with dementia as less than human, and their experiences, views, and rights to choose have not been recognised (Kitwood, 1997). Such views are embedded within the established and authoritative biomedical model of dementia, where psychosocial aspects of care have been marginalised and the focus has mainly been upon physical care, meeting basic needs and controlling problem behaviours with the use of drugs (Kitwood & Benson, 1995).

Although the feasibility and importance of applying empowering practice to people with dementia is now more widely recognised, there is still little research that takes account of their views (Reid et al, 2001; Adams & Manthorpe, 2003). This is particularly true of those people in mid and later stages of dementia, and of research focusing on issues such as quality of care (Moriarty, 1999).

This study, which falls within a broader investigation of dementia, care and communication patterns (Vass et al, 2002), explores the possibilities of empowering people of a range of severity of dementia by eliciting accurate views and experiences from them, about dementia and care provision and in particular quality of care. Relatives' experiences are also explored. As a research assistant working on the wider project, I selected this aspect of the study as a focus for this PhD study.

The project was carried out within Jewish Care, a health and social care charity for the Jewish Community. Jewish Care was selected for a number of reasons, for example, they were keen to investigate the experiences of people with dementia, and were happy to support the use of multiple methods and a flexible approach to the research, in order to achieve this. Although research was carried out solely within Jewish Care settings, it is considered that many of the findings from this study may be more widely applicable. The experience of dementia is similar, whether the individual is Jewish or of another culture. In addition, apart from those that are of a religious and cultural nature, many of the needs and values of Jewish people with dementia, relating to quality of care, are similar to those of non-Jewish people.

This thesis is divided into two parts. The first consists of four chapters, which give some background to the project and describe the study that was carried out. Chapter One focuses on the different types of dementia and on different models of dementia care. Chapter Two explores past and current care provision and legislation. Chapter Three discusses existing research on service user empowerment with regard to people with mental health problems, older people and more specifically people with dementia. Chapter Four describes the study which was carried out and sets out the aims, the rationale for carrying out this particular project, the methods employed and the scope of the investigation. Part two consists of six chapters which explore the results of the study. Chapter Five presents an overview of the results. Chapter Six and Chapter Seven discuss the perceptions of people with dementia and their relatives about residential and day care services. Chapters Eight and Nine explore the experiences of people with dementia and their relatives about dementia. Chapter Ten concludes the thesis and discusses the findings, the implications and recommendations which arise from them.

In order to maintain confidentiality, participants' names are not used in the thesis, but are replaced with pseudonyms. In addition, parts of the thesis are written in the first person and the third person singular 'their' is used frequently in place of she/he. It was considered this would be less cumbersome and additionally there are unresolved issues about whether the masculine or feminine gender should be used and which should come first. For these reasons, 'their' is increasingly being used in this way and left unaltered by copy editors (Burchfield, 2004, p.776).

The concept of service user empowerment is used as the theoretical framework of this study, and is therefore a central theme throughout this thesis. A definition of empowerment suggested by Grace, 1991 (cited in Doohar & Byrt, 2003, p.35) is "*the notion of people having power to take action to control and enhance their own lives, and the processes of enabling them to do so.*" Therefore in practice, empowerment involves service users being in a position where they are able to make their own choices and decisions and maximise control in their lives (Morris, 1997). There are a number of processes which can facilitate empowerment, and these may include supporting individuals to develop their own abilities and confidence and professionals developing their skills to help people with dementia to empower themselves (Thompson & Thompson, 2001). Empowerment can take place at different levels, so apart from helping service users to develop autonomy, it can be about changing oppressive culture, organisation and structures in care settings and in the wider society (Thompson & Thompson, 2001). Empowerment is about "*working with people who are oppressed, not just to increase their say and control, but also to challenge the source of their oppression*" (Tanner, 1998, p.448). These elements are central to this study.

Terms such as service user involvement and participation are potentially empowering processes with specific meanings which are used in relation to empowerment. A definition of user involvement given by Harrison and Mort (1998, p.60) is, "*a local attempt to include organised groups of service users in the planning, and occasionally the management, of such services.*" User participation on the other hand is defined by Byrt (1994, cited in Byrt and Doohar, 2002) as, "*...the involvement of service users in responsibility and/or decision making, which has an intended impact on services and/or policies which affect the individual participant and/or other service users*" (p29). User involvement and

participation may therefore entail empowering people with dementia by encouraging them to play an active role in their care; asking their views about services and policies; and working in partnership with them. They can take place a different levels, from individual care to governmental policies and global issues and also at different degrees, from consultation to complete responsibility. User participation is more likely to be associated with greater responsibility and involvement in decision making in a wider community sense, where as user involvement tends to be used in relation to a specific service. It is considered to be a less proactive process, which is strongly associated with consumerism (Byrt and Dooher, 2002), an issue which receives further attention in chapter three.

Empowerment can be seen as a theory, underpinned by certain values, which aim to enhance personal well being, promote autonomy and challenge inequality and oppression; it can also be seen as a practice, if and when the theory is applied to real situations. There are several different dimensions to empowerment and a number of models have been proposed in the last decade (Hogg, 1998; Wilkinson & Miers, 1999; Fingfeld, 2004). Three which are particularly relevant to this study are Byrt and Dooher's four-dimensional model of empowerment (2002), Thompson's three-level 'personal, cultural and structural' analysis framework (1998), and Wright's four-level model of user involvement (1999), as between them they take into account empowerment at an individual level which relates to people with dementia; they consider staff attitudes and service and organisational structures; they acknowledge the extent of influence and control that individuals have; and they include quality of life issues, equal opportunities and rights. These issues impact severely on care and are thus integral to this study which explores quality of care and life for people with dementia. These models in particular, and the literature on empowerment in general, inform the theoretical framework underpinning this study.

Byrt and Dooher's and Thompson's models are similar, in that the different levels/dimensions correspond closely with each other, however they each have something extra to offer, and therefore are both used. For instance, Byrt and Dooher's model consists of an important additional dimension and includes quality of life issues which are relevant to this study. Thompson's model, on the other hand, focuses on issues relevant to older people and Wright's model is helpful, as it considers the different levels that individuals can be involved at.

For the purposes of the study, empowerment is conceptualised at four different levels. The first level, which both Byrt and Dooher (2002) and Thompson (1998) refer to is called the 'individual level of empowerment.' This can be applied collectively as well as individually, as it can be a shared experience (Thompson (1998). It refers to 'the individual's belief and ability to have power, influence or control' (Byrt and Dooher, 2002) and includes the person's own skills, such as their ability to articulate their needs and wants; levels of self-esteem and self-confidence; and self-efficacy or belief in the capacity to bring about change (Byrt and Dooher, 2002). For empowerment to be possible at this level, the person needs to possess particular skills such as communication ability and confidence and a professional's job would be to support these. This study examined the possibility of empowering people with dementia at an individual level, by investigating whether they are able to express accurate views and opinions on issues such as services and thus take an active role in and have power, influence and control in the planning, delivery and evaluation of services.

Cognitive deficits and low self-esteem may affect the levels of empowerment achievable, but professional attitudes and behaviours can exacerbate or diminish difficulties experienced. Kitwood's malignant psychology (1997) is an example of this. He describes practices which disempower the person with dementia by fostering dependence. These include, not allowing individuals to make their own choices and do things for themselves, when they are able; and those which treat the person with dementia like a child or like an object, rather than a person. Kitwood argues that these have a malignant effect on the person, adversely affecting their self-worth and diminishing their personhood. They may impact on abilities and self-esteem, components of the first dimension. The way that professionals and their organisations treat people with dementia relates to the second dimension of empowerment in this framework, which is the 'organisational/professional level.' Empowerment relates to the extent to which care professionals are willing to support service users to empower themselves (Byrt and Dooher, 2002; Thompson, 1998). It includes their readiness to communicate with and consult with individuals and how empowering their attitudes and behaviours are. It may involve professionals examining and perhaps revising their practices; considering whether these are demeaning; whether they reinforce traditional stereotypes; and if they help to sustain patterns of inequality and

power. It is important that attention is paid to language, imagery and stereotypes which are sometimes disparaging and derogatory. Older people are often perceived very negatively (Thompson, 1998). Ageist attitudes and behaviours are so deeply embedded within our culture that they are sometimes invisible. Professionals also need to develop their own skills so that they are in a position help individuals to empower themselves; much self awareness may be required in order for them to do this (Thompson, 1998). The organisational level also includes the cultures and structures within the organisation to enable empowerment and participation (Byrt and Dooher, 2002). This study explores attitudes and behaviours of professionals towards people with dementia; the systems and structures present within services; and how empowering or disempowering these are for people with dementia and their relatives. However this does not aim to replicate the body of knowledge that currently exists, but to provide data from a different perspective, that is from the perspectives of people with dementia.

The third level is called the ‘service-user power level of empowerment.’ This dimension exists in Byrt and Dooher’s model, but is omitted from Thompson’s model (1998). It refers to ‘service users’ actual achievement of desired change, power or control’ (Byrt and Dooher, 2002) and includes components such as consultation, information, choice, having a voice, autonomy, participation and involvement in decision-making, control, influence and power. Service users may have varying levels of control and therefore Wright’s model (1999), which details how individuals can be involved and thus achieve power at different stages, is integrated at this level of empowerment. The first stage relates to providing adequate information, so that individuals know what is happening around them or to them and are able to make informed choices; the second stage involves gathering ideas and consulting with individuals; the third entails working with and involving individuals, such as inviting them to meetings and working groups and the fourth and last stage involves supporting user-led initiatives. This study examines the levels of influence and control that people with dementia and their relatives have over their lives and care and whether they are able to make their own choices and decisions.

The fourth and last level of empowerment is referred to as the ‘societal-inclusion level of empowerment.’ This fourth dimension, which exists in both Thompson’s and Byrt and Dooher’s models, considers the structured patterns of prejudice within society, which

include social categories such as age, class, gender, race and disability. It involves challenging the existence of these divisions which disempower some groups of people, such as those who are older or mentally ill, by allocating them low status, power and social resources (Thompson, 1998). It relates to the achievement of social inclusion, equality of opportunity and equal rights and involves social and political changes and freedom from discrimination in the wider society. Components of this dimension include equality in relation to life opportunities and quality of care, e.g. with regard to privacy, independence, relationships, choice and activity; liberation from prejudice, stereotyping and other negative attitudes; and political power (Byrt and Dooher, 2002). This study examines empowerment at this level as it explores quality of life for people with dementia and their relatives and examines how people with dementia are perceived and treated. Byrt and Dooher (2002) suggest that for maximum empowerment to occur, individuals need to be empowered in relation to all four of the above levels.

It would be all too easy to undertake this investigation in a detached and sterile way which reinforced the disempowerment of people with dementia. Therefore a major objective of this study was for involvement to be empowering for individuals with dementia and their relatives. Chapter four discusses this issue and when demonstrating how this was achieved, reference is made to the framework above and also to the empowerment literature explored in chapter three.

PART ONE

**Theoretical Background and Approach to the
Study**

1 DEMENTIA

This chapter provides background information on dementia, examining its causes, symptoms, progression, methods of care and treatment. When exploring the latter, two models are usually considered and these are the biomedical and psychosocial models of dementia care, both of which are reviewed in this chapter. In the past, treatment and care of people with dementia was dominated by the biomedical model, however in recent years this model has attracted much critique which includes assertions that its practices and attitudes are very disempowering. More recently, the psychosocial model of dementia care has emerged. This promotes a more empowering approach, by placing an emphasis on quality of life; taking account of the views and feelings of people with dementia; and by recognising and building on the skills and abilities which remain, rather than on those which are lost.

(1.1) Dementia within the context of the medical model

The medical model, which originated in the study and practice of biomedicine, focuses on pathological processes and disease. Within this framework, dementia is seen as a clinical syndrome which results from disease of the brain. It may present in a number of different ways and it has many different causes. A description of dementia given by the World Health Organisation is:

'Dementia is a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is a disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. Consciousness is not clouded. Impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. This syndrome occurs in Alzheimer's disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain'(World Health Organisation, 1992, p.45).

Causes of dementia include degenerative brain diseases, such as Alzheimer's disease, the most common cause of dementia, Fronto-temporal dementia, Lewy Body dementia; and Cerebrovascular diseases such as vascular dementia. Dementia is generally, but not always progressive (Rabago & Bayer, 1998).

From a neuro-pathological viewpoint, Alzheimer's disease is thought to occur because of the disruption of brain neurotransmitters, such as Acetylcholine, due to abnormally low levels of enzymes that are critical for their synthesis. This leads to neuronal death (Eastley, 1998). The memory, language and spatial problems associated with Alzheimer's occur as a result of widespread atrophy in the brain, which is most marked in the temporal lobe and hippocampus, which are associated with memory and in posterior parts of the brain which are involved in language, visuospatial and practical abilities. Additionally, damage to the frontal lobe of the brain may result in changes to behaviour, personality and impairment of social judgement (Dickson, 2001). Neurofibrillary tangles and plaques progressively develop in the brain (World Health Organisation, 1992). So far, no one single factor has been identified as a cause of Alzheimer's disease and there is currently no cure for it, although a number of drugs have been developed which may temporarily relieve some of the symptoms.

Vascular dementia is the second most common cause of dementia after Alzheimer's Disease. It can occur suddenly after a single stroke or in a stepwise fashion, after multiple strokes (World Health Organisation, 1992) and in some cases, where people have small vessel vascular disease, it progresses more slowly and gradually. Deprivation of oxygen results in death of brain cells (Brown, 1999). It is thought that those people who have high blood pressure, a high level of fat in their blood and diabetes are at greater risk of developing the disease and it can therefore be to some extent contained or delayed, for example, high blood pressure can be controlled through diet, lifestyle and drugs. Dementia with Lewy bodies, which has received increasing recognition over the last decade is now recognised to be another very common form of dementia (Serby & Samuels, 2001). It is characterised by tiny spherical structures made of proteins that develop inside nerve cells, which lead to the degeneration and death of brain tissue. Cognition is impaired and with this there are attention and problem solving deficits, visual hallucinations and motor

features of Parkinsonism (Henderson, 1998). Smaller categories include Picks disease, fronto-temporal dementia and infectious causes of dementia, such as Creutzfeld-Jakob disease (CJD), syphilis, HIV and AIDS. In addition, there are alcohol related dementias, dementias associated with Parkinson's disease, Huntingdon's disease, Wilson's disease, Supranuclear Palsy and Multiple Sclerosis. Some of these conditions are treatable and others are irreversible.

The clinical picture of dementia is characterised by deficits in cognition which are apparent in all individuals from an early stage. These include memory impairment and at least one of the following: aphasia, apraxia, agnosia or a disturbance in executive functioning (American Psychiatric Association, 2000). Non-cognitive, behavioural, physical and neurological symptoms may also develop as the disease progresses (Dyman & Passmore (1999; Cooper & Greene, 2005). Cognitive symptoms associated with all forms of dementia include memory impairment, which typically begins with short-term memory loss, resulting in difficulties such as finding the right words, repetition of the same question, problems learning new material or recalling previously learned material, mislaying everyday objects and so on (Cooper & Greene, 2005). Long-term memories may be well preserved at the beginning, but deteriorate as the disease progresses, so the person may eventually forget their occupation, family members and even their name (American Psychiatric Association, 2000). There is some variation depending on the type of dementia, for example, episodic memory is particularly affected early on in Alzheimer's disease (Eastley, 1999) and someone with fronto-temporal dementia would typically find that their memory is relatively intact at the beginning and personality and behaviour affected more (Burns, 1999). As the disease progresses, the person with dementia becomes increasingly disoriented. Early on, individuals tend to mix up the time and day and can feel lost in unfamiliar environments and later on in the disease the person may become confused between night and day and feel disorientated even in familiar places. They may also lose the ability to recognise familiar and significant people. Language difficulties (aphasia) are also experienced, which initially present as name and word-finding difficulties, simplification of content of what is being said or empty-speech, and some problems with comprehension. These difficulties gradually become worse, as language skills disintegrate as the disease progresses. The person will gradually lose their ability to read and write. Other cognitive symptoms include problems with performing sequential tasks (apraxia),

e.g. dressing, eating or making a cup of tea. The person may also experience changes in perception (agnosia), that is they may lose the ability to recognise objects such as chairs, pencils and people and problems with executive function are common, i.e. the person may have difficulty with problem solving, organising and planning. There is also impairment to abstract thought, reasoning and judgement (American Psychiatric Association, 2000; Iliffe, 2001).

Pathological deficits and changes in the brain may also sometimes result in non-cognitive symptoms. These include apathy and mood disorders such as anxiety and depression (Dynam & Passmore, 1999). Changes in personality and behaviour may also occur in the mid and later stages of the disease and early on in fronto-temporal dementia (Cooper & Greene, 2005). Typical problems include inhibition, inappropriate and unsociable behaviour (Burns, 1999), as well as angry and aggressive behaviour and wandering (Dynam & Passmore, 1999). Delusions and hallucinations tend to be experienced in the mid stages of the disease, although these may occur early on in Lewy body dementia, particularly visual hallucinations, which often take the form of animals and people (Eastley, 1999). In addition, there may be physical changes such as weight loss, especially with degenerative dementias. People with vascular dementia are more likely to be obese. Swallowing problems are common later on in the disease and loss of continence may occur. Neurological signs are also observable, for instance, Lewy body dementia is often associated with Parkinsonism (Serby and Samuels, 2001). Primitive reflexes and exaggerated tendon jerks are sometimes observable (Cooper & Greene, 2005).

Within the biomedical framework, a number of drugs have been developed. These are not a cure, but some claim to alleviate symptoms and even slow down the process of dementia. However, because of widespread ageism in health policy, many older people are denied access to the drugs on account of their cost, although they are known to be effective. They include, Aricept, Exelon and Ebixa (Molinuevo et al, 2004; Chick, 2005; Jones, 2004). Other drugs prescribed are for behavioural problems, mood disorders, depression and anxiety (Bullock, 2004; Steinberg, 2004). Work is constantly being carried out to develop more effective drugs with less side effects.

Until recently, the medical model has dominated debates about dementia and been the focus of treatment or rather the inability to treat dementia. It has a number of strengths which lie in it being grounded in the well-established biological sciences. The basic concepts are measurable and objective and it has a well-defined sequence of methods: syndrome, aetiology and treatment. It presupposes that different conditions can be diagnosed and treated and physical treatments are often able to bring quick relief. There is a certain respectability that a psychopathological syndrome gains as a disease, when it has a definite underlying biological pathology as a critical feature. Years of biomedical research, with sensational successes such as the eradication of smallpox have attained much respect and trust for this model (Rosenhan & Seligman, 1989). Despite difficulty in researching neurological illnesses such as dementia, because of the complexity of the nervous system, medical research has resulted in a greater understanding of the disease in terms of brain abnormalities and neurotransmitters, which has sometimes led to new types of treatment. As a result of medical knowledge and the development of new technology it is possible to diagnose dementia and establish the specific form and drugs may be offered to alleviate some of the symptoms. It may be somewhat reassuring and empowering for the person with dementia and their relative to know of the diagnosis as it allows an opportunity to plan ahead for the future. It is possible that knowledge and understanding of dementia could be further advanced, were there not widespread ageism in medicine, for instance, drug companies will not always fund dementia research, their preference being to fund research relating to younger people's medical needs and illnesses.

However, many aspects of this model which attributes the experience of dementia solely to a disease process, and which concentrates predominately on the neurobiological factors when considering causes, progression, care and treatment of dementia have been criticised and challenged. It has been claimed for example, that practices and attitudes advocated by this model are very disempowering for people with dementia. Adherence to the biomedical model and neglect of psychosocial aspects of care restricts quality of life and opportunities available to individuals with dementia, thus undervaluing and disempowering them. Since there is no clear cause of dementia and there is no cure for it, it is afforded low status. Treatment is confined to basic care, such as feeding, bathing, providing a safe environment and managing undesirable behaviours with the use of drugs. As such, people with dementia are denied a quality of life which is accessible and enjoyed by many others. Wider factors

which can influence quality of life such as psychological and social needs are neglected (Cottrell & Schulz, 1993). For example, many people experience depression, insecurity or fear alongside the neurological disorder and these feelings can exacerbate their neurological symptoms (Rosenhan & Seligman, 1989), however they are virtually ignored by the medical model, other than prescribing drugs to try to eliminate them. Issues such as social relationships, stimulation, choice, independence and the individual's personhood are also marginalised. There is a lack of any psychosocial intervention, which it has been demonstrated could greatly improve the quality of life of people with dementia (Kitwood, 1997).

The practices of organisations and professionals working within a biomedical framework can also disempower people with dementia because quality of life is not promoted. The abilities and skills of individuals are not recognised, because the medical model assumes that old age equates with physical and intellectual decline. The focus is on the disease, deterioration and hopelessness, compounding neurological and psychological problems. The medical model undervalues individuals who are conceptualised as passive recipients of care and not as people who have the capability to have control and influence over their lives. It is often perceived that they are relatively incapable, have nothing very meaningful or valid to say and it is the professionals who are the experts who know best (Thompson & Thompson, 2001). These negative attitudes and practices will inevitably impact on the other levels of empowerment, for example, they may affect empowerment at an individual level, diminishing self-esteem and belief in the ability to have influence or control.

(1.2) The Psychosocial Model

In the last decade in Britain, attitudes towards dementia have changed somewhat, and moved away from a focus on brain pathology to perceiving the individual with dementia as a person in their own right, with their own experiences, feelings and needs (Brown & Hillam, 2004). These changes have been the result of the work of several people, in particular a social psychologist, the late Tom Kitwood. In an article of 1987 and in a later report of 1989, Kitwood put forward a case that neural degeneration is not the only explanation for dementia, but psychological, social and environmental factors are likely to

play an important role in its development and progression. This presented a challenge to the biomedical model of dementia.

He supported his assertion in a number of ways, first of all by highlighting the lack of correlation between the degree of dementia and the extent of the neuropathology or brain damage in moderate or severe dementia. Evidence for this is provided by studies such as those of Snowden (1996; 1997), which show that sometimes a person with dementia can function at a high level, when they have severe brain damage. Conversely, others show little pathological change, but have high levels of disability, findings which suggest that other factors are likely to be involved. The World Health Organisation (1992) also acknowledges that changes in the brain and clinical features of dementia do not always progress in parallel. *'One may be indisputably present with only minimal evidence of the other'* (p.47).

Kitwood also brought attention to diseases and problems such as cardiac arrest, some cancers and diabetes, which were once ambiguously labelled as organic, but have now been attributed psychological factors. He highlighted a phenomenon called 'Rementia,' which refers to some degree of recovery from dementia. Rementia, he argued, may not only occur when drugs are used, but psychosocial factors could also contribute and are important to consider. Attending to psychological and social issues helps to reduce any excess disability which occurs in addition to the neuropathology (Sixsmith et al, 1993; Evidence-Based Mental Health, 2004). In addition, Kitwood argued that on many occasions it appears to be a major event or crisis in someone's life that suddenly brings on the dementia, or progresses the illness, and to explain this as simply neural degeneration is not appropriate. Examples of this may include death of a loved one or loss of roles.

The above issues all suggest that other factors in addition to brain damage may have an important role to play in the manifestation and progression of dementia. These ideas are central to the psychosocial model of dementia care, which takes account of neuropathic change, but puts an emphasis on psychosocial aspects of care, which until recently have been ignored. Within this framework there is an attempt to understand or make sense of the behaviours and feelings of people with dementia within a psychological and/or social context. For example, it is suggested that withdrawal or aggressive behaviour may not

simply be symptoms of the disease, but perhaps could be understood as a response to the way the person is feeling inside. Perhaps they reflect the emotional pain the person is in as a result of the changes and losses they are experiencing or they could be seen as a reaction to the social environment, as perhaps the person feels their independence is being taken from them and their dignity undermined. Likewise, a person may be anxious or confused because their situation is changing and they are frightened of what the future may bring; they may wander because they feel bored and understimulated; or be agitated because they are in pain, hungry or in need of the toilet. Various studies have shown that so called problem behaviours may be a form of communication expressing unmet needs and not simply symptoms of the disease process (Watts, 2003; Trilsbach, 2002; Ragneskog et al, 1998). There is evidence to suggest that other experiences such as coping abilities and awareness of difficulties can also be influenced by psychosocial factors (Pratt, 2003; Clare, 2002).

The psychosocial model aims to meet psychological and social needs. It is potentially more empowering than the medical model, as it employs a holistic approach and thus a better quality of care for people with dementia. It challenges oppressive practices and attitudes, striving to offer people with dementia the same life opportunities that many others enjoy. It looks further than the basic aspects of care and takes account of wider social, psychological and environmental factors and needs which can impact on quality of life, for instance, unlike the medical model, it recognises the need for social stimulation. The benefits of stimulation for improving wellbeing of people with dementia have been demonstrated by several studies. For example, Opie et al (2002) found that 'challenging behaviours' were significantly reduced when multi-disciplinary interventions, which incorporated psychosocial approaches such as sensory stimulation, massage, aromatherapy, social interaction and reminiscence were used with residents with dementia in a nursing home. Similarly, Stoker & MacDonald (1999) found that daily multisensory and activity sessions reduced behaviours such as screaming and shouting. Van de Winckel et al (2004) found a musical exercise programme effective for improving cognition in people with dementia and Smith (2004) found that hydrotherapy, which puts an emphasis on people with dementia having fun and letting go in a swimming pool, reduced wandering, increased social interaction and stimulation and expression of enjoyment.

The psychosocial model also acknowledges the psychological impact of dementia, for example the feelings of grief, denial, depression and loss of self-esteem which are commonly experienced (Bryden, 2002). It recognises the need for appropriate support and intervention, for example, grief counselling, psychotherapy, group, family and cognitive behavioural therapy (Bryden, 2002). Benefits of these types of intervention for people with dementia have been demonstrated by Cheston et al (2003) who found that a psychotherapy group reduced the levels of depression and anxiety experienced by people with early and moderate dementia. Verkaik et al (2005) found some evidence to suggest that multi-sensory stimulation, behaviour therapy and psychomotor therapy can reduce levels of depression, aggressive and apathetic behaviour in people with dementia. Psychoeducational groups (Dyck, 2003; Bender & Constance, 2005) and counselling (Bartlett, 2003) can also help to improve wellbeing.

The psychosocial model can be empowering in the sense that it acknowledges the rights of people with dementia to a high quality of care and to be heard, included and valued. There is acknowledgment that each person with dementia is a unique individual, with their own experiences, abilities, needs, wants and preferences (Stokes, 2002; Brown & Hiram, 2004). The model takes account of the perspectives, needs and wants of people with dementia (Mackie, 1997; Gilliard, 2002) and this in itself may enhance empowerment at an individual level.

The psychosocial model recognises the abilities which remain with the individual and the person's rights to independence and autonomy and it strives to maximise potential (Dewing, 1999; Jackson, 2002). Empowering practice at an organisational/professional level would involve professionals working to encourage and support individuals to develop their skills, abilities and confidence, thus supporting empowerment at an individual level. An aim is to compensate for disability by finding out what the individual can and wants to do and finding ways to support them, thus enabling and empowering them (Kitwood, 1995; Bell & McGregor, 2000; Gilliard, 2002). The focus of the model is on providing a helpful and constructive environment, where the person with dementia can re-discover and re-build aspects of themselves which may have previously been stifled (Mackie, 1997), allowing them to build up their self-confidence and self-worth.

Within this framework, various rehabilitative interventions for people with dementia have been proposed. Brenner and Brenner (2004) describe a rehabilitative method, based on work of Dr Maria Montessori, which also focuses on identifying the strengths and abilities that are retained by the person with dementia and on maintaining independence. The theory underpinning this approach is that some abilities relate to experiential learning through performance, rather than memory. So, although a person may not remember their past activities and abilities, they may retain the practical skills. In the Montessori method, these abilities and interests are identified and presented to individuals with dementia in a manageable format; if necessary they are broken down into small steps, each step is practised and the environment is adapted to the needs of individuals. A number of studies have attempted to evaluate this method and results have been positive. Vance and Johns (2002), for instance, revealed that Montessori materials can positively influence cognitive abilities of attention, object permanence and social behaviour in individuals with Alzheimer's disease. Gorzelle et al (2003) trained home care workers to implement Montessori-based activities when interacting with people with dementia and were impressed by the results. Among other positive effects, there was a statistically significant increase in pleasure. Schneider and Camp (2002) found Montessori-based activities increased engagement in individuals with dementia in long-term care and Orsulic-Jeras et al (2000) found this type of intervention effective for reducing negative behaviours (Mountain, 2004).

Several studies have also pointed to the usefulness of cognitive rehabilitative intervention. For example, in Clare et al's study (2003), a retired teacher, Bernard, was able to recall names of people in his support group, which he previously had difficulty remembering, after undergoing this type of intervention. The study employed the use of a mnemonic strategy which involved Bernard generating associations between photographs of members and their names. Bernard then rehearsed and practiced recalling names by using these associations. Results of the study indicated an increase in recall from 2.31% to 91.46%, an improvement which was largely maintained at follow-up periods of one, three and six months. Robinson (2003) found combined intervention, which involved cognitive behavioural therapy to reduce feelings of negativity and anxiety and cognitive rehabilitation which focused on using external memory aids, such as diaries and notebooks, effective for reducing anxiety and improving memory in an individual with dementia. In another study,

in which individuals with dementia received twice-weekly cognitive stimulation therapy sessions, consisting of reality orientation, reminiscence, current affairs and multi-sensory activities, cognitive function of individuals with dementia improved (Evidence-Based Mental Health, 2004). These studies provide evidence that psychosocial forms of intervention can be effective in enabling people with dementia to make the most of their remaining skills.

However, the psychosocial model has not escaped criticism. Adams (1996) for example, has discussed some of the problems with Kitwood's work, which mainly relate to his research methods. He suggests that Kitwood has spent too much time discussing his views, and not enough time talking about how he developed his ideas and presenting his data. Some of the studies carried out to evaluate the usefulness of psychosocial interventions have been criticised for being small scale and using methodology that is weak (Mountain, 2005). Building an evidence base in this area can be difficult and takes time and it is not always appropriate to use randomised controlled trials in this field. Woods (2003) argues that there is a need to be more open to other approaches and forms of evidence which can support this model. There has also been some critique of the person-centred movement, an important aspect of the psychosocial model. It has been suggested that the concept is too 'idealistic' and 'unrealistic' (Packer, 2000). It is all too easy to change the language in publicity materials to that of a 'person-centred' type, but much harder to put the concepts into practice. Packer (2000) argues that to put person-centred care into practice effectively will require much hard work; more time is needed, as well as methodological development, and evaluation and dissemination, before person centred approaches will become accepted and put into effect. Packer's assertions may well be correct, as it is often the case that policies or ideas exist in theory, but they are not always put into practice. This issue is explored in this study. Baker et al (2003) have emphasised the importance of both carer involvement and an organisational strategy if person-centred care is to be developed effectively, where as others such as the Kings Fund (2001) have argued that adequate funding is required in order to develop and implement high quality services.

Conclusion

In conclusion, the medical model of dementia, which focuses primarily on neurobiological factors, perceiving dementia mainly in terms of a disease process, has contributed a great deal to our knowledge of dementia, neurological processes and causes. It has been successful in developing not a cure, but drugs which may help to alleviate symptoms of some individuals. In the past, this model has dominated approaches to treatment and care, however, in recent years, it has been the subject of much criticism, not least because of the disempowering practices it promotes. In the meantime, the psychosocial model of dementia has gained increasing support. This model focuses on empowering people with dementia by promoting their quality of life; recognising their rights; building on and maximising their strengths and skills and including rather than eliminating their perspectives. While there may be room for criticism of this model, it provides a more holistic and humane approach to care and it has the potential to greatly improve the quality of life of people with dementia. All people in receipt of care services, including those with dementia, have a right to care beyond that of a basic physical nature. Psychological, emotional and social needs are of equal importance. In addition, everyone, including people with dementia, has the right to make choices and decisions for themselves and to have their feelings and perspectives heard and taken into account. This view is central to this study.

2 CARE PROVISION AND LEGISLATION

This chapter explores care services and related legislation for people with dementia, both within statutory services and within the Jewish voluntary sector in England. Attitudes and behaviours towards people who are older and those who are mentally ill, which can impact on services, are also examined. People with dementia fit into both of these groups. This background information aims to put the study into context.

The chapter shows how people with dementia and more generally older and mentally ill people have been disempowered by practices within society. They have experienced much discrimination, which has resulted in inferior life opportunities and quality of care. Chapter One explored different models of dementia care and their implications for services. These included the traditional biomedical model of dementia, which is disempowering in the sense that it neglects psychosocial needs and the person, focussing predominately on the disease and the tasks associated with meeting physical needs, and the more recent psychosocial model which advocates more empowering approaches. However, although the psychosocial model and related policies and legislation exist in theory, it is debatable how many of the good intentions which aim to enhance the quality of care for people with dementia have been put into practice. There is a need for more research in this area and in particular studies which incorporate the perspectives of people with dementia themselves. This perspective is lacking and it is important to include it, as even thoughtful and well-intentioned care may not be a good experience from the recipient's point of view. Further research in this area could help to identify strengths and weaknesses in current care provision and improve services for people with dementia.

(2.1) Care services for people with dementia

In the UK public sector, there are currently a number of services in place for older people, including individuals with dementia. Services provided by the Jewish voluntary sector, in which this study was carried out, closely parallel these. Because of the vast sums of money required to provide care for older people, Jewish community services have become

increasingly integrated with more general UK services in recent years and consequently what affects the UK as a whole also affects the Jewish Community (Valins, 2002).

Current social services for older people, including those with dementia, comprise of 'domiciliary care,' that is personal care such as bathing and dressing, help with preparing meals, shopping, occupational therapy and chiropody. Day centre support is also available, which includes centres which cater for older people more generally and more specialised day centres which provide care specifically for people with dementia. Other services include sheltered housing, respite and institutional care, such as residential and nursing homes. Importantly there are also informal or family support networks in place. Approximately 5.7 million people provide informal support for their spouses, friends, neighbours or relatives, most caring for four hours a week or less, but some 800,000 for fifty or more hours (Valins, 2002).

This study was carried out within Jewish Care, which is the largest health and social care charity for the Jewish Community, supporting almost 7,000 people a week. Among the groups of people that it caters for are physically disabled, visually impaired and older people, providing residential, day, home and dementia care. All homes and centres are situated within London and South East England.

As mentioned services provided by the Jewish community are similar to those which exist in the public sector. For instance, Jewish social service agencies have been set up in cities where there are many Jews and these are able to organise various domiciliary services, equivalent to those provided in the public sector. Day centre support is also provided. There are 21 Jewish day care centres for older people across the UK. Some provide transport and almost all of them a Kosher lunch as well as other refreshments and a variety of activities, similar to public sector provision. Special day care centres, which are specifically for people with dementia, also provide a range of activities, transport and kosher meals, but they provide a higher level of care and cater to the needs of people with dementia, again paralleling public sector services. Residential and nursing care is also available. London has the most facilities, reflecting the dominance of Jewish Care in the Southeast, which provides almost two thirds of the Jewish voluntary sector bed spaces in London. Other services include relatives' support groups, counselling and an Admiral

Nurse Service. Jewish Care also has its own social work service which liaises with local and health authorities to access the full range of services available including those provided by Jewish Care (Jewish Care, 2004). It is also important to remember the semi-formal structures of care provided by the Jewish Community for older Jewish people. Synagogues provide lunches or friendship clubs for older people and the Association of Jewish Friendship Clubs co-ordinates the activities of around 50-60 such clubs. Activities include speakers, entertainment, activities and welfare information. The UK contains four main strictly Orthodox communities which all have their own systems of self-help (Valins, 2002).

In addition to social services, public sector community health services are also available to individuals with dementia. Community psychiatric nurses can offer nursing assessment and practical and emotional support and practice and district nurses make home visits and provide nursing and monitor support required. Help is also on offer from health visitors, continence advisors, psychology and old age psychiatry services, chiropodists and the dentist. In addition, hospital services are available, which include speech and language therapy, respite care, physio and occupational therapy. Consultants can assist with diagnosis and drug treatment and so on. Lastly there are voluntary sector organisations such as the Alzheimer's Society. Local branches run support groups, counselling and provide educational and social support. .

However, although there are a wide range of services on offer to people with dementia, the quality of these services has been questioned. In an attempt to address the shortfalls and reflecting increasing levels of empowerment at a societal-inclusion level, recent governmental policy and legislation has sought to modernise, regulate and enhance older people's services. There is an emphasis on independence and empowerment in many of these policy initiatives (Cantley, 2001). In 1998, the government published its White paper, "*Modernising Social Services*" and this, in conjunction with the *NHS plan* (2000) and the *National Service Framework for Older People* (2001), has several aims. Firstly, in order to assure standards of care, the Care Standards Act was passed in 2000 and national minimum standards were introduced to regulate care homes and domiciliary services in April 2002 and April 2003 respectively. Before then, services were regulated and inspected

locally by local authorities and therefore there was little consistency in standards throughout the country. Day care services are still regulated by local authorities.

National standards for care homes apply to seven key areas and these include choice of home; health and personal care; daily life and social activities; complaints and protection; environment; staffing; and management and administration. The standards aim to empower older individuals, by enhancing their quality of life and giving them greater control and influence over their lives, for example, they aim to provide choices for older people and their families with regard to the home they select or go to. The home must meet the needs of and be able to care for the individual, for example, kosher food should be provided in a home caring for Jewish people. Care plans should be drawn up for each person in consultation with them and these should reflect the needs and wants of residents in relation to issues such as health, personal care, daily life, activities and personal and social relationships and should be reviewed monthly to reflect changing needs. Residents' interests should be recorded and their social and recreational needs should be met. They should be provided with opportunities for stimulation through leisure and recreational activities in and outside the home, which meet their needs and preferences. Up-to-date activities should be circulated to all residents in a format suited to their needs and abilities. The standards require that certain groups of people are given particular attention and include people with dementia and other cognitive impairments. There is an emphasis on user autonomy, choice and involvement and a requirement that residents are helped to exercise control over their lives in all aspects of their care. In addition, the person's rights to privacy and dignity should be upheld at all times and homes are required to have a policy on protecting residents from abuse which should be a 'no secrets policy,' where any suspicions or incidents of abuse should be reported immediately. The physical environment should be safe, well maintained and meet the needs of residents. From 2005, 80% of rooms should be single and all single rooms should be at least 10 square metres and should be adapted to the needs of the individual. There should be a six-month induction programme for all new staff and by 2005, 50% of care assistants should be NVQ level 2 qualified, managers should have expertise in caring for older people and if it is a nursing home they should be a 1st level nurse. By 2005 managers must have an NVQ level 4 qualification in management or an equivalent qualification (Nazarko, 2002).

National standards for home care services consist of five main areas. These are user focused services; personal care; protection; managers and staff; and organisation and running of the business. The focus of the standards is mainly on personal care and not on social care, as it is argued that there are day centres to provide more socially orientated care. An emphasis has again been placed on service user involvement and empowerment. The standards require that there should always be a Care Needs Assessment and care should meet the needs of individuals as specified in the care plan. Individuals should be provided with adequate information and enabled to make choices concerning their care and a responsive and flexible approach to care should be taken. In addition, the rights, privacy and dignity of individuals should be respected at all times; there should be a staff development and training programme in place and specialist advice, training and information should be provided for care workers working with specific user groups and/or medical conditions (DoH, 2003).

A second governmental aim has been to ensure fairer funding and access to care for older people. This is another step towards empowerment, as it reflects increasing recognition of older people as individuals with equal worth and rights to others in society. For instance, as a result of a report by the Royal Commission, "*With Respect to Old Age*" (1999), changes have been implemented so that the nursing element of care in a home is free and the value of residents' homes is disregarded during the first three months. Upper and lower capital limits for paying fees have been raised. Local authorities have often spent less on older people and more on younger people. The Royal Commission on Long Term Care (1995) calculated that local authorities are spending an average of 16% less than the standard spending assessment on services for older people while spending more on younger disabled people or on children. Moreover there is currently no framework for councils to determine the eligibility criteria with regard to who should receive social care services, so there are wide variations in the practices of different local authorities. To address this, the Department of Health published a consultation draft: '*Fair Access to Care Services*' (2001) which provides guidance to councils for setting eligibility criteria by which individuals receive or do not receive local authority social care support. In addition, in its White paper: '*Modernising Social Services*' (1998), the Department of Health promised an extra three billion including 1.3 billion for a social services modernisation fund.

Other developments include single health and social care 'personal plans' for older people and their carers and new intermediate care services to allow older people to live more independently (National Service Framework, 2001). New legislation and policy which focuses on providing person-centred care, maximising independence and involving service users in the planning and development of services has been issued. For instance, The NHS Plan (2000) allocates a whole chapter to empowerment and involvement of patients, proposing more power and influence for them over their care and services. Proposals include more information for patients; patient advocacy and liaison services and patients' forums. Direct payment schemes have been introduced for people over 65, which aim to give older people more control and influence over services they use. The new green paper: Independence, well-being and choice (2005), which sets out a vision for adult social care over the next 10 to 15 years, aims to increase control, choice and quality of support for all service users.

However, although the intention to empower and improve quality of care for older people seems to be there, difficulties have been encountered when seeking to implement the initiatives described above. For example, Rowe & Shepherd (2002) have identified a number of problems relating to involving the public in primary care services, a major goal of the NHS Plan. Difficulties include a lack of skills and support and the attitudes of both professionals and the public. The public are not always willing to get involved and sometimes professionals do not take views of local people seriously and there is sometimes uncertainty about how to go about involving them. Another issue relates to a lack of funding. An inquiry into care and support services by the King's Fund, "*Future Imperfect*" (2001), argued that the quality of care and support falls far short of what service users and carers should be able to expect and that to address this a massive boost in funding levels is required. There needs to be a substantial increase in resources if the government is to meet its current goals with regard to providing high quality social care services for older people and that there needs to be a realistic assessment of the costs (Robinson, 2005; Garfield, 2002; Valins, 2000; Kings Fund, 2001).

Because of financial problems, local authorities minimise their costs and commission services that are cost effective, which tends to limit these only to those with the highest levels of need. To gain local authority funding for long-term care, residents have to

demonstrate ever-greater levels of need and therefore tend to be older, frailer and have higher levels of disability or long-standing illnesses. Many councils concentrate too much on minimising costs, rather than on the effectiveness of the services they seek to provide or commission and the quality of services suffer, and even those with very high needs do not receive the care and support they need to maintain their health and well-being, and independence, safety, dignity and choice are restricted and people are made to wait for support (Valins, 2002). The combination of implementing the Care Standards Act (2000) and under-funding by the local and health authorities has had a major impact on the residential and nursing home sector. The result has been the closure of many homes.

The lack of funding has also impacted negatively on Jewish community service provision. Most Jewish voluntary sector homes have a majority of state funded service users, but there are pressures on local authorities to reduce spending and they will only pay 70-80% of the costs of care. This creates financial problems for individual institutional care providers which have to pay the difference. With increasing demands from service users and the introduction of national minimum standards these problems are set to deepen (Garfield, 2002). Problems reflect the difficulties experienced in wider social services, such as domiciliary care and if these financial problems continue, costs and or services will have to be dramatically cut or there will have to be increased support from the Jewish community.

To minimise the threat to the independent care home industry from limitations in local authority funding, the government launched a new agreement between the statutory and independent sectors: *“Building Capacity and Partnership in Care”* (DoH, 2001). As a result, councils can be much more flexible in terms of the amounts they pay to independent sector organisations, which should reflect the assessed needs of the service users they are funding. However it has been argued that there is insufficient investment to support such initiatives (Garfield, 2002) and this is in competition with funding for education, children etc. However, under the *Race Relations (Amendment) Act* (2000) which explicitly includes Jews and is reaffirmed under the *National Service Framework for Older People* (2001) and the *NHS Plan* (2000), councils and other statutory bodies have a fundamental duty to provide culturally appropriate care and could in theory be legally challenged if they fail to do so. At the same time though, the government aims to provide culturally appropriate care

within mainstream provision, so implications for the UK Jewish Voluntary sector are unclear (Valins, 2002).

The huge problems related to the funding of long-term care are likely to increase as the number of older people in the UK increase. This reflects a number of different factors such as the post war baby boom, higher standards of living and advances in medical technology which contribute to longevity. In a report entitled “*With Respect to Old Age*” (1999), the Royal Commission estimated that in 1995 costs of care for older people was one billion pounds and that this would increase to 14.7 billion in 2010 and to 19.9 billion in 2051. The National Minimum Standards have put further financial pressures on local authorities; and another major issue is ageism. Ageist attitudes and practices result in older people being denied fair access to resources and the quality of care they are entitled to.

(2.2) Ageism

Ageism is defined as “*systematic stereotyping and discrimination against people because they are old*” (Victor, 1994, p.77). Although the process of ageing is universal, older people are often perceived to be distinct and different from the rest of the population and they are treated as a homogeneous group and not as individual people. The person is no longer a person who happens to be old, but an ‘old person,’ and old age becomes the major identifying characteristic of the individual (Victor, 1994). Ageism can disempower older people at virtually all levels of the empowerment model. At a professional/organisational and societal-inclusion level, older people have to contend with disempowering attitudes and behaviours from others, which stem from negative stereotypes and beliefs held by individuals, organisations and/or society. These include assumptions that older people are incapable, dependent and relatively unimportant compared to the rest of the population (Graham et al, 2003). Attributes such as independence and personal autonomy are highly valued in society and people who may not have these traits are viewed as inferior. The economic and social status of older people is low, because they are perceived as a non-productive group who are sometimes financially and physically dependent (Victor, 1994; Kane, 2002). Issues such as decline in physical attractiveness, withdrawal from respected roles and the loss of partners and friends (Cohen, 2001) all contribute to older people being seen as ‘less’ than others. Apart from influencing people’s attitudes towards older people,

stereotypes may also be internalised by older people themselves, who start to act in ways that are expected of them, or as they are seen by others. Stereotypes communicate to older people appropriate forms of behaviour (Victor, 1994) and they may impact negatively on abilities and self-esteem at an individual level of empowerment.

Ageism may stem from genuine care for a person where there is a desire to protect the older person, because it is felt that they cannot protect themselves. Things are done for the individual, rather than allowing them to do what they are able to do, thus undermining their independence. Other forms of ageism are not based on compassion but come from neglect and from discounting the needs of older people. They disempower older people by depriving them of social status, diminishing their self-esteem and denying them a fair share of social resources (Madge, 2005). Different cultures behave differently and hold different attitudes towards older people, suggesting that ageism may be culturally constructed (Scrutton, 1990). In Jewish culture older people are highly regarded, but in western industrialised societies, the process of ageing is not looked upon favourably. In British society we are all subject to negative and disempowering images of older people from an early age. School text books often portray older people as frail and pathetic, and not as people who may possess valuable skills and abilities. Language can help to perpetuate negative attitudes towards older people and diminish their self-esteem and self-worth. Commonly used phrases such as 'old biddy' and 'mutton dressed like lamb' depict a caricature of what an older person is supposed to be as opposed to what they are. Medical opinion also has a major influence on people's attitudes and can be very disempowering with images of increased periods of sickness, loss of mobility and energy, incontinence, confusion and senility. Beauty has been associated with youth throughout history and by implication old age is linked with ugliness, so today people still go to great lengths to look young. Older people are thought to be unattractive and this is compounded for women since sexist attitudes and beliefs suggest that it is more important for women to be attractive than men (Scrutton, 1990). Older people sometimes buy into these negative stereotypes and promote the idea of staying young forever (Cohen, 2001).

Ageism is apparent in a number of different areas, both locally and at a national level. It is not limited to the general public, but has been reinforced by the structures in place in society, which makes it much more difficult to address than if it were only a matter of

individual attitudes (Ward, 2000). Ageist practices have resulted in restricted opportunities, unfair treatment and an inferior quality of care for many older people. For example there are compulsory retirement ages which diminish social status and promote ideas of older people as a burden and disablement benefits are often less for older people than for younger disabled people and some cannot be claimed after pensionable age. Ageism is apparent in care services (Little, 2005). For example, the Health Advisory Service (2000), who carried out a study into the care of older people on acute wards and in general hospitals, encountered prejudice towards older people and their care at almost every level of the service system. There are often fewer trained and qualified staff working with older than with younger people (Hughes, 2000; Little, 2005); many care staff in nursing and dual registered homes have little or no training. The King's Fund Inquiry into Social Care, 'Future Imperfect' (2001) showed that almost three out of four of staff have no qualifications and moreover they argue that there is a correlation between poor training and poor workplace practice. Low wages make it difficult to recruit staff into a stressful and complex job, especially when they could be paid more for stacking shelves in a supermarket (Valins, 2002). Policies have sometimes been ageist and fewer resources have been allocated to older people (Kane, 2002) and the abuse of older people in residential homes is not taken as seriously as the abuse of children who are thought to represent the future. Reflected in the bias of local authorities towards funding younger people's services rather than those of older people, it is sometimes thought that the needs of older people are not as important as those of younger people. Older people tend to be marginalised and their rights and status as citizens are affected (Fennel et al, 1994).

Some people may face a double or even triple jeopardy (Graham, 2003). For example older women may be discriminated against because they are both older and female (Victor, 1994); while black older people face discrimination because they are older and black and perhaps female. People with dementia are jeopardised because of cognitive impairment and age, bearing a double of stigma of having mental health problems and one of old age (Graham, 2003).

The government attempts to address the issue of ageism in the National Service Framework (NSF) for Older People (2001). However, a study carried out by the Kings Fund (2002) indicates that while the majority of managers support the move to combat age

discrimination, they lack the practical tools for the job. They feel unsure about how to identify age discrimination in health practice and whether age related policies and practices are ever justifiable. The report concludes that the Government's stated objective of eradicating ageist practices from the NHS will not be achieved unless local managers are given more help to implement this policy. It is important to remember that people with dementia may experience further disempowerment and discrimination. There may be less recognition of their rights, status, skills and abilities as not only are they "old," but they have mental health problems and they have to contend with the stigma attached to this (discussed below). Additional work will need to be carried out to eradicate discrimination in services for people with dementia and this includes seeking their views and feelings on the services they receive and on how these may be improved.

(2.3) Stigma

The stigma attached to mental illness can further disempower people with dementia. The concept of stigma involves attitudes, feelings and behaviours. Stigmatisation occurs when a negative label is placed on an individual or group, when they possess an undesirable characteristic, which marks them out as different (Benbow & Reynolds, 2000) and this results in fear, prejudice, discrimination and stereotyping (Kenny, 2001). Stigma is the result of a number of factors referred to by Kenny (2001) as external and internal stigma. External stigma refers to unjust treatment from others and internal stigma refers to the negative feelings of shame, low self-esteem and guilt which are experienced by individuals. Stigma may result from ignorance, as people with mental illness are sometimes viewed to be strange, unpredictable, unreliable and incompetent and society values characteristics such as independence, prestige and money (Kenny, 2001). Negative stereotypes result in people with mental illness being feared or viewed as inferior to others and incapable in a similar way to older people, which can be very disempowering for them. Projection of these types of attitudes and feelings can affect levels of empowerment at an individual level, adversely affecting self-esteem, self-perception and beliefs in ones' own abilities. Stigma has been shown to increase the burden of people with mental health problems and act as a major barrier to recovery. It may result in feelings of isolation and reluctance to seek help and support (Crisp, 1999).

It is sometimes thought that the stigma attached to Alzheimer's and other forms of dementia is not as pronounced as that attached to other mental illnesses. However, although dementia involves changes in the structure of the brain and chemistry it still attracts the stigma of a psychiatric illness and in addition, people with dementia have to contend with the stigma attached to old age (Graham et al, 2003). Individuals with dementia are sometimes depersonalised, they are viewed as old, burdensome, ugly, dependent and as mentally unstable and contact with them often arouses anxieties in others which result in avoidance and exclusion (Kitwood, 1997, cited in Benbow & Reynolds, 2000). The stigma associated with the label 'mental patient' or 'demented person' and resulting prejudices often make it extremely difficult for individuals to assert their rights and can result in individuals being disempowered by health care professionals and other people around them. Stigma may result in decreased employment, affect relationships with others and it can lead to discrimination in all segments of society, which can then impact on self-esteem and result in demoralisation, which in turn may impede self-recovery (Kenny, 2001).

Conclusion

In conclusion, services for older people including those with dementia may not be what they should be according to current legislation. Despite new legislation and policies, which are anti-ageist and supposedly seek to empower individuals and improve standards of care, changes are slow to occur. Appropriate standards of care and practice may exist in theory but for a variety of reasons are not put into practice and thus the level of empowerment, and quality of care which is received by people with dementia, may be open to question. The stigma attached to old age and mental illness still prevails and this can be very disempowering for people with dementia, impacting negatively on the way they are perceived and treated by society and on the services that are provided for them. There is a need for further research in this area, particularly that which incorporates the perspectives of people with dementia themselves, since they are in the best position to provide information about the quality of services they receive and on how these services can be improved. To date, there is much existing research which incorporates the views and experiences of carers, but little which takes account of the perceptions of people with dementia. The importance of including the views of people with dementia is discussed

further in chapter three as well as the feasibility of eliciting views from this group of people.

3 PERSPECTIVES ON SERVICE USER EMPOWERMENT

(3.1) The concept of empowerment

Definitions and models of empowerment encompass a wide range of issues, from individuals being in a position to make their own choices and decisions to equality in relation to life opportunities and social resources and freedom from discrimination. Since powerlessness embraces a number of issues, i.e. it has economic, environmental, social, emotional and cognitive implications among others, empowerment must address all of these problems in order to be meaningful (Davey, 1999). Terms such as 'user involvement' and 'user participation,' are commonly used, but although these are potentially empowering processes, they are not necessarily in themselves empowering.

A useful starting point in the discussion about empowerment would be to distinguish between consumerist and empowerment approaches to user involvement, since the two are frequently confused. The consumerist approach implies that individuals should be able to choose from a range of services or products (Barnes and Walker, 1996). The idea is that these will be of high quality and responsive to needs, because if they are not, users will select a competitor. Regular monitoring and evaluation of services are key to a consumerist approach. It has been argued however that this approach is restricted in terms of the power and influence that it allows individuals and it makes a number of questionable assumptions. For example, it assumes that alternative options are available, whereas in reality this may not be so for everyone. An older person may not have a choice to move to another residential or nursing home and some individuals may not be in a position to explore other options and shop around (Barnes & Walker, 1996).

The empowerment approach goes further than the consumerist approach, as it seeks to involve service users in the development, management and operation of services, as well as in the assessment of need (Barnes & Walker, 1996). This type of involvement relates

closely to the concept of 'user participation,' discussed earlier in the thesis. Service users are involved in making decisions about the future direction of the organisation, rather than simply commenting on a particular service and they have the influence and power to make a difference (Rowe & Shepherd, 2002). There is a potential for achievement of change. Participation could otherwise simply be referred to as 'tokenism,' where individuals are offered opportunities to be involved at a superficial level but have no power to make a difference (Byrt & Dooher, 2002). The ability to participate fully depends on the extent to which service users are allowed any real power by professionals. It also reflects the degree to which they are perceived as being equal to other members of society and as such, entitled to make decisions about matters which affect them. This issue is referred to later in this thesis, when examining the levels and extent of empowerment in the settings investigated and in the research conducted.

There are concerns that an empowerment approach to involvement is not employed within health services, as involvement ends in little change. In Litva et al's study (2002), members of the public were able to see that their involvement did not change decisions and they wanted some guarantee that their views and opinions would be heard and wanted explanations for decisions made after consultation. In other words, they wanted 'accountable consultation.' Harrison et al (2002) argue that there is a lack of evaluation in this area, as few studies have attempted to establish the extent to which decisions have been influenced by involvement, although those which have been conducted have found limited evidence of this. Among these studies is Harrison and Mort's (1998) which revealed that although a number of health authorities consulted the public through health panels, none agreed to be bound by their decisions. They ensured they were able to disregard the decisions made if they did not agree with or like them.

The nature of the relationship and the power balance between professionals and service users are important to consider and relate to professional and organisational cultures and practices; they are not unrelated to factors at the level of the individual, such as self-esteem, knowledge and skills. Empowerment is of limited value if it does not extend to the service user/professional relationship (Greenwell, 1996). Hawkins (1996), for example, refers to the doctor-patient relationship. Going to see the doctor was often a disempowering experience, but in recent years, more importance has been attached to the notion of 'equal

partnership working' (Greenwell, 1996). Consequently steps have been taken to reduce the inequality or power imbalances which can impede empowerment and result in patients passively accepting treatment and care they are given, rather than engaging in an active partnership. Changes in the doctor-patient relationship include the reduction of waiting times; efforts are now made to provide comfortable seating in waiting areas; good lighting; information; perhaps even music....all of which convey the message that patients are becoming more valued and accepted as equals. The structured interview where the doctor would ask all the questions, is usually replaced by a less formal approach and patients are being encouraged to talk freely without being interrogated (Hawkins, 1996). These issues are addressed later in this thesis, when considering and examining professional-service user relationships, both in terms of relationships between the researcher and participants and those between service users and careworkers in the residential and day centres evaluated.

It is crucial to stress the importance of the notion of 'equal partnership,' as empowerment does not simply involve the handing over of power from professionals to service users, but it relates to working in partnership and making use of the knowledge and skills of both parties (Barnes and Warren, 1996). Barnes and Warren (1996) argue that trust is an integral element for the establishment of relationships which empower users. However, these should not disempower workers, since a reciprocal relationship of trust has advantages for both parties. This has relevance for research as well as practice, as researchers are now challenged to treat service users as participants in rather than subjects of the research process, an issue which receives further attention in chapter four. Critics of this approach however argue that although an equal relationship or partnership between the researcher and participant is desirable, this may not be achievable in practice. Stacey (1991, cited in Richardson, 1997), suggests that this approach fails to recognise the differences and unequal relationship between people as researchers and people as subjects.

Barnes and Warren (1996) identify some further principles of empowerment which they believe should underpin attempts to empower service-users. First of all, at the level of individual empowerment, they state that empowerment should enable personal development, as well as increase influence over services. Byrt and Doohar's (2002) and Thompson's (1998) models state that personal development is often a pre-requisite to empowerment, but Barnes and Warren (1996) go further in suggesting that personal

development should be an outcome of empowerment, not just a precondition. An empowering approach, they argue, intends to produce change in people as a result of the process of participation, so that apart from involvement leading to changes and improvement in services, involvement is in itself beneficial. This may be particularly important when changes in services are slow and individuals who participated, for example, in some research to evaluate the effectiveness of a service they use, do not have time to wait for and reap the benefits of any long-term improvements. Personal development through the process of involvement may include increased self-esteem, abilities, skills and knowledge.

Secondly, and at the individual level, Barnes and Warren (1996) suggest that 'empowerment should aim to increase people's abilities to take control of their lives as a whole and participate in wider arenas, not just increase their influence over services.' This should involve enhancing individual self-esteem and confidence to enable individuals to articulate their views about other issues in their lives and in other contexts. A third principle is that 'empowerment of one person should not result in the exploitation of others: either family members or paid carers.' Family carers for example, may be viewed as a resource to be utilized and exploited by statutory services, who use their presence to justify not providing a service. There is a need to take account of the views and needs of carers as well as service users and these should not be overlooked or devalued. Carers are entitled to support for themselves and to have their wishes and perspectives taken into consideration and this may contribute to the empowerment of direct service users, as with adequate support carers are in a better position to provide good quality care. In addition, family carers have knowledge of the person's past interests, likes and dislikes which they could communicate to service providers, if the person is not able to do this themselves, potentially enhancing quality of life (Barnes and Warren, 1996).

Fourthly, at the level of professional practice, empowerment must be reinforced at all levels within service systems (Barnes and Warren, 1996). Thus empowerment should take place at an individual level as well as involve obtaining collective feedback on services and facilities. It would be disempowering and frustrating for individuals to be involved in overall service development, but then have little say at an individual level about care received. As discussed earlier, the empowerment model requires participation in decision

making and changes in the way that those responsible for services undertake their responsibilities. It is not satisfactory for service providers to obtain individual or collective feedback and then use their discretion over whether or not to use it. This inevitably means changes in the decision making processes within services; in the relationships between service-providers and service users; in service planning and monitoring; and in the recruitment and training of staff. The need for a whole organisational change is explored in this study when examining levels of empowerment in residential and day care settings investigated.

A fifth principle identified by Barnes and Warren (1996) relates to committing adequate resources to empowerment initiatives. It is not satisfactory and largely unethical to obtain views from service users and then tell them that nothing can be changed because of inadequate resources. This would be extremely frustrating and disempowering for them. Sixthly, 'empowerment should be a collective as well as an individual process as without this people will become increasingly assertive in competition with one another' (Barnes and Warren, 1996). This differs to a consumerist approach, where service users are viewed as individuals who seek to maximise their own satisfaction, without taking account of individuals with similar needs. Consumerist approaches could be detrimental to some, e.g. those who are not as able or as confident to express their wants and needs individually. The empowerment approach recognises the need for service users to collectively assert their views and make decisions about a particular policy or service received in order to benefit all. Service users may also identify their collective interests in order to empower individuals through their identification with others. Barnes and Warren (1996) argue that empowerment should extend beyond individual services, and even beyond service users collectively to the collective involvement of all citizens in decision making about services. All citizens are not currently active users of services, but may be need of them at some point in the future and can therefore be seen to have an interest in them and are entitled to some say and input into them. As taxpayers and voters all citizens have the right to a say in decision making about policies and resources and therefore some influence in developing a welfare system which can benefit all in society.

The importance of service user empowerment has been increasingly recognised over the years. However, as was discussed in chapters one and two, people with dementia and more

generally older people and people with mental illness have not always been empowered adequately. For instance, they have not always received a high quality of care or been allocated a fair share of resources and they have been subjected to negative stereotypes, attitudes and behaviours from professionals. They have had restricted opportunities for choice, involvement and participation, and have been disempowered at all levels of the empowerment model. Several reasons have been identified for the lack of empowerment, which include ageism, stigma, a focus on the biomedical model and a lack of investment in resources for people with dementia.

In the past, professional practices and organisational cultures have adhered to a paternalistic and medicalised approach to service provision, underpinned by the belief that the professional is the knowledgeable and experienced party in the relationship. They therefore decided what was best for the individual and what was needed. There was an assumption, often referred to as 'welfarism,' that those who are older or unwell need to be looked after and that the provision of care is the primary if not the sole focus. Individuals were seen as the recipients of care, rather than as people who could influence care provision and actively participate in decision making and in their care (Thompson & Thompson, 2001). People with dementia were doubly disadvantaged, perceived as being both "old" and having a mental illness. Their views were rarely heard or given any real value or worth and their rights to autonomy were not recognised. This view has been challenged by the empowerment model, which argues that it devalues the individual and what they could offer and contribute. Welfarism adopts a restricted view of older people's needs and thus reduces them to recipients of care without recognising broader needs and rights. The empowerment model aims to redress the power imbalance between service users and professionals, as rather than being perceived as experts who know best and should take control, professionals are identified as enablers and facilitators who use their skills to support and help individuals to influence and take control of their own lives and empower themselves (Thompson & Thompson, 2001). Until recently, the views of people with dementia have also been omitted from research and consequently there are a limited number of studies which include and take account of their opinions and feelings, an issue which receives further attention later in this chapter.

Attitudes have started to change in the last decade and there has been protest about the way that people with mental illness and older people, including those with dementia, are perceived and treated. There has been a call for revision of past practices and attitudes and more empowering services for these groups (Campbell, 1996). This is reflected in the emergence of the psychosocial model of dementia and in new legislation and policies, which incorporate issues such as service user autonomy and choice, although the extent to which they are being put into practice is open to question. This wave of change has extended to research, where more studies are seeking to involve people with dementia.

This study drew upon these new ways of thinking and sought to include people with dementia by involving them through eliciting their views and opinions directly. It was generated from and underpinned by theories of service user empowerment. The project examined the possibilities of empowering people with dementia at an individual level, by exploring ways of communicating with them about their needs, wants and experiences. Some of the wider factors which can impact on empowerment, such as levels of self-esteem and service users' belief in their ability to have power and influence were also explored; as well as staff and organisational issues and structures; extent of actual influence or change achieved; and levels of social inclusion and change. An additional aim was for participation in the study to be empowering for people with dementia and their relatives and ways in which this was achieved are discussed in the next chapter.

The chapter now proceeds to discuss the importance of empowerment, past and present attitudes towards it and the feasibility of empowering people with dementia by eliciting accurate information from them, thought in the past to be near impossible because of cognitive impairment.

(3.2) Service user empowerment within mental health services

Since the Second World War, there has been continual movement towards increasing the civil rights of disadvantaged groups in western industrialised countries. The importance of service user empowerment has been increasingly recognised and this has touched on mental health (Campbell, 1996), where there has been a shift towards user empowerment which was particularly notable in the 1980s (Bowl, 1996). The changes that have taken place are

largely a result of the influence of other countries, such as America and the Netherlands, but more importantly, they are a product of years of dispute and protest by people with mental health problems at the way they are treated and viewed by society (Campbell, 1996). Movements and protests have taken place as far back as the 17th century and include, the petition of the poor distracted people in the house of Bedlam and the works of the alleged Lunatics' Friend Society and the Lunacy Reform Law Association, following the establishment of the asylum system in the mid and late 19th century. In the 1970s, the Mental Health Patients Union was established and the Anti-Psychiatry Oppression Campaign and the Disability Rights Movement took place. People with disabilities protested about their increasing exclusion from society and demanded that society change their attitudes and behaviours towards them. These are all examples of collective empowerment (Barnes and Warren, 1996) where service users collectively asserted their rights in order to combat oppression and achieve change in their circumstances. In the 1980s, groups such as the BNAP (The British Network for Alternatives to Psychiatry), CAPO (The Campaign against Psychiatric Oppression), Mind and Voices (a network of those diagnosed with Schizophrenia) and several self-help groups were set up and in 1985, mental health service users had the opportunity to put forward their viewpoints at the national Mind annual conference for the first time. From 1985 to 1995, the number of independent user groups increased from under 12 to over 350 (Campbell, 1996). Attempts were made to implement empowerment at a societal inclusion level, as legislation, such as the NHS and Community Care Act (1990) and the National Framework for Mental Health (1999) was passed which requires the participation of service users in care planning and provision. Overall, there have been a number of developments, although as discussed later in this chapter, some issues concerning implementation of empowerment within mental health remain problematic.

(3.3) Service user empowerment and older people

The importance of empowering older people has also now been recognised, although progress has lagged behind the empowerment of other groups of people such as those with mental illness or learning difficulties (Thompson, 2001). This may be because of widespread ageism in society (Lima et al, 2003). Older people have been described as among the most disempowered groups (Thompson & Thompson, 2001). At a societal-

inclusion level, they are disempowered by poverty, inadequate housing and discrimination in health and social care services (Hughes, 2000). For example, less money is allocated to older people's services in comparison to services for younger people, thus transport may be unsuitable or unavailable, and access to health care may be delayed (Graham, 2003). Additionally older people are sometimes viewed as a homogeneous category rather than as individuals, they are prone to negative stereotypes and are regarded as a problem because of concern about the cost implications of increasing numbers of older people. Disempowerment is also apparent at a professional/organisational level, although it is frequently well intentioned. Older people are subjected to negative stereotypes and behaviours from professionals, who often view them as frail, dependent and helpless and as people who need looking after, rather than as persons who can take control of their own lives and influence services (Dooher & Byrt, 2003). It has also been suggested that professionals tend to accept the views and wishes of carers rather than the older person, thus disempowering them, which differs from behaviours towards other groups of people such as younger and disabled people, where professionals are more likely to support service users (Parsloe, 1996). Older people may also be disempowered at an individual level. Thompson (1997; cited in Thompson & Thompson, 2001) highlights a number of reasons why older people may be less likely to become active participants for personal reasons, which include internalised oppression, where individuals may absorb the negative and ageist stereotypes and attitudes about older people which may lead to a reluctance to challenge inequality and to a lack of skill and confidence; and a higher incidence of illness and disability which may for example, prevent attendance at consultation meetings and may result in communication difficulties which can impact on levels of user involvement. External problems can further exacerbate difficulties, for example, lack of transport and other people's behaviours. Older people may also lack awareness of the possibilities or avenues for involvement or influencing services. They may assume that it is not their place to have a say unless they are encouraged by others such as professionals, relatives or advocates.

(3.4) The importance of empowerment

There are many benefits of empowering service users, which relate to the different levels of the empowerment model used. At an individual level, empowerment may increase

wellbeing and result in personal development. Empowerment may serve to enhance health, skills, knowledge and preserve dignity (Cohen, 1991). Several evidence-based examples of empowering initiatives are cited in the literature. For example, Melling (2003) who created a sensory garden in partnership with people with dementia, suggests that by involving service users and consulting with them about their needs, individual satisfaction was increased and feelings of alienation reduced. Supporting people with dementia to be as independent as possible has been shown to have a positive effect on their mood and well-being (Burgener et al, 1993 & Teri & Logsdon, 1990). The Fife User Project, set up in Scotland to give older people an opportunity to express their views, needs and experiences of community care services, had a positive effect on self-esteem and confidence and also enhanced knowledge and learning. Participants felt more confident to articulate their views and influence change, and they were able to learn more about services and about the way other people addressed their difficulties, by sharing experiences with them (Cormie, 1999). Empowerment may also result in individuals feeling more confident about taking control over other aspects of their lives (Barnes and Warren, 1996).

At the level of the service-user, empowerment may lead to more power and influence. Involving people with dementia in their own care and in important issues that affect them may help them to gain a sense of control over their lives; it also demonstrates respect for autonomy (Drickamer and Lach, 1992; cited in Downs, 1997). At a professional/organisational level, professional knowledge and services better adapted and more responsive to the needs of individuals may be developed. By consulting people with dementia about their illness and about the care they receive, it is possible to gain first hand knowledge of services and also of the disease and how it affects the individual and about the coping mechanisms they employ (Robinson, 2002, Ostwald et al, 2002). Bahro et al (1995), who explored the coping strategies used by people with dementia, suggest that an increased knowledge of these can help us understand the function of certain behaviours and increase our tolerance for them, thus improving care. Likewise, Bender and Cheston (1997) suggest that increased understanding of the feelings of people with dementia can have a positive effect on care services. A lack of understanding leads to the attribution of so called challenging behaviours directly to the illness, rather than viewing them as appropriate emotional reactions to particular situations or events. By working in partnership with people with dementia, care and professional knowledge may be enhanced

(Clarke, 1999), through an increased understanding of the 'internally lived world' of the person with dementia (McKee, 1999), thus in order to assure equity and equality for people with dementia, services that are more responsive to the needs of people with dementia are developed. Learning from people with dementia about their experiences of their condition and of care provision can help us develop and improve services based on their wants and needs (Keady et al, 1995) and hence enhance quality of life. Phinney (1998) argues that research which takes account of the person with dementia, has the potential to humanise care and that if attention is given to the perspectives of people with dementia, services supporting the person's sense of self-worth and which help the person to find meaning in their day-to-day lives can be developed.

Information about the experiences of people with dementia has frequently been sought from relatives or carers rather than from the person with dementia themselves. However, many older people may not have relatives to speak on their behalf and although there is often an assumption that carers' views are reliable (Clare, 2004), it has been suggested that carers or relatives may lack information and insight about the experiences of people with dementia. A study by Kemp (2002), for example, examined the accuracy of information obtained from proxies about the person with dementia and found inaccurate information in 40 percent of cases. Brooker (1997) argues that a highly satisfied relative does not necessarily imply a highly satisfied service user and that service users needed to be consulted directly about their experiences. Similarly, Cottrell and Schulz (1993) argue that opinions and perspectives of carers may not always correspond with those of the person with dementia. They suggest that carers may sometimes be biased due to having a bad relationship with their relative, or because they are depressed. They also consider that studies which use proxy respondents, reduce the individual to the status of object, rather than perceiving them as someone who can contribute to the study being undertaken.

However, despite changes in attitude, legislation and policy and increasing awareness of the importance of empowerment, it is questionable to what extent the concept of user empowerment is currently put into practice. Although these days, the rights of service users to have a say in services is acknowledged, there is very little evidence of this change in attitude in current research and practice. Service user involvement has been described to be simply lip service (Ross, 1995), because although choices are offered, decisions

continue to be made by professionals. Bowl (1996), in a national survey exploring the prevalence of user committees in day care centres and residential establishments, found that although they were present in most authorities, there were very mixed feelings about them. They were described to be meaningless by some, others saw them as purely advisory, whereas some perceived them to be very important.

Many reasons have been identified for the lack of empowerment, for instance, organisational structures and cultures may impede empowerment. It has been suggested that a gap exists between intent and outcome, as undoubtedly many health care professionals intend to practice in an empowering way, but in reality face many difficulties. Because of the need to balance the competing interests of different groups of people, such as professionals, politicians and the government's fixed agendas, service users' views often do not make a difference (Goss and Miller, 1995). In addition communication and contact between service users and those who make key decisions about services may be scarce or non-existent. Service users may not be present when key decisions are made and may therefore have very little opportunity to influence services (Department of Health, 1996).

Professional knowledge or lack of knowledge may also hinder empowerment, as professionals may have incomplete knowledge about how to involve service users and what people want from services (Department of Health, 1996). There is a need for clarification of terms such as user empowerment and user involvement (Kuokkanen & Leino-Kilpi, 2000; Boehm & Staples, 2002; Finfgeld, 2004) and for further discussion, education and training about these issues (Barnes and Bowl, 2001), because people have different perceptions about what they mean, their purpose and how they should be implemented. Lack of knowledge and understanding may result in a reluctance on the part of care professionals to change their ways of working and introduce user empowerment into practice (Honey, 1999). They may be frightened because they think it may mean that they no longer have as much control and their practices and authority may be questioned.

Additionally, professional attitudes, beliefs and behaviours may be problematic and impact on the levels of empowerment achieved. Professionals commonly believe that an individual or group of mental health service users cannot represent anyone's interests other than their own, as these are not generalisable to others. Service users have opposed this

idea, feeling devalued and undermined and perceiving double standards set by agencies. The views of service users are often disregarded, because it is claimed that they do not represent all users, but it is also probable that professionals do not represent all the disciplines involved in care (Beresford and Campbell, 1994). The stigma associated with the label 'mental patient' and 'disabled person' can seriously impede empowering practice (Krogh, 1998; Johnstone, 2001; Finfgeld, 2004). Many prejudices held by professionals and the wider society, often make it difficult for people with mental health problems to assert their rights. Not only do service users have to contend with the limitations placed on them by their disability, but also with the stigma attached to their label (Koplow, 1981). The views of service users are often disregarded, as they are attributed to the individual's illness or thought to be mere fantasy. Bowl (1996) reports from his survey of user committees, that many service users felt they were not allowed to have a say in real issues, only in domestic issues. He quotes one committee service user member, who said that her views and comments were never minuted in meetings, as the person taking minutes put down their pen whenever she spoke. Older people with mental health problems may face a double jeopardy because in addition to the stigma attached to mental illness, they have to contend with the stigma attached to old age. Older people are sometimes viewed to be intellectually incapable and equated to children (Victor, 1994), which may mean that their views and opinions are even less likely to be heard.

Socialising agents such as the media may exacerbate problems experienced and further disempower individuals. Lynch and Thomas (1994) discuss the misportrayal of people with disabilities as victims in the media. According to them, the victim model is incompatible with the empowerment model in suggesting that people with disabilities are helpless, dependent and at the mercy of the environment. It suggests that people with dementia are the victims of a progressive and irreversible disease. 'Victim mentality' messages are endemic and are invariably internalised by people with disabilities and impact on their self-esteem and self confidence. Rather than being a victim of circumstance, empowerment entails maximising opportunities and encouraging people to use their full potential to take control of their own lives. Lynch and Thomas (1994) suggest the real difficulties facing people with disabilities should be given more attention, especially in relation to discrimination and societal attitudes. People with mental health problems are

invariably portrayed as frightening and strange creatures who are best avoided and these negative portrayals serve to perpetuate negative stereotypes, beliefs and attitudes.

At an individual level, people with mental health problems may lack confidence as a result of institutional practices and because of the way they are perceived and treated by others. Older people with mental illness face a double jeopardy, as they also have to contend with ageist attitudes and practices which they may have internalised. In Ross's study (1995) service users reported the need for training in assertiveness, group work and confidence building if they were to actively participate in service planning. Bowl (1996) argues that few staff are expected to participate in service planning and delivery without any training, and therefore service users should also receive this training, but they are not routinely offered this opportunity. In situations where service users have been given training in staff selection procedures and equal opportunities, the outcome has been very positive, boosting self-confidence and spurring them on to participate further. In addition, service users are not always aware of their rights and of current legislation (Ross, 1995; Tanner, 1988). Ross's study (1995) demonstrated that service users were scarcely aware of the community care legislation and its implications for user empowerment. People who use services may also lack knowledge and information about methods of complaining, about the services available to them and their rights to quality and effective care.

Other reasons identified for the lack of service user empowerment include a lack of resources and a drive to contain costs (Ross, 1995; Tanner, 1998). Tanner describes obstacles such as 'targeting, economy and efficiency' being put in the pathway of user empowerment. These issues may be particularly applicable to older people, as less resources have been allocated to older people's services because younger people's services are prioritised.

Problems with empowering practice may be more widespread than currently known. Mental health service users or their carers are often afraid to be critical about the care services they receive. Ross (1995), who interviewed people with physical disabilities, learning difficulties and mental health problems found that service users were often reluctant to disclose their true feelings about services or to be critical, even when they were assured of confidentiality. This reflected past experiences where criticism had

repercussions for themselves and their care. Elliot (1997) and Barnes (1998) found that older people are rarely critical when expressing views about services, as they often have very low expectations of care, have nothing to compare with, or are fearful of expressing criticism and wish to please staff.

(3.5) Service user empowerment and dementia services

There have been even fewer opportunities for empowerment for some mental health groups and these include people with dementia. While some efforts have been made to involve certain groups of people, legislation that requires service user involvement has not always addressed and been applied to people with dementia adequately. For instance, *The Working in Partnership policy* (DoH, 1994) does not properly address older people, but relates more to younger people with mental disorders, which according to Adams (1996) reflects the absence of an adequate definition. More recent reports and policies have referred specifically to older people with mental health problems and made some reference to involving people with dementia in their care and hearing their views. For example, 'Forget me not,' a report produced as a result of a study carried out by the Audit Commission (2000), recommends that the quality of care in homes is monitored and that this process should include surveying the views of service users and/or carers. In addition, when somebody is moving into a residential or nursing home it recommends that: "*Social services should aim to involve a range of professionals, as well as users and carers in decisions to admit people to residential and nursing home care, to ensure that the services provided best meet the needs of the user*" (p.80). Likewise *The National Framework for Older People* (2001) and *The National Minimum Standards for Care Homes* (2002) and for *Domicillary Services* (2003) have emphasised the importance of service user involvement, choice and autonomy and give particular attention to people with dementia. *The National Health Service and Community Care Act* (1990) which also applies to people with mental health problems including those with dementia, aimed to provide enough support to enable people to live as independently as possible in their own homes, while giving them a say in their care and how they live their lives. It also aimed to promote partnership between service users, carers and service providers. However it has been suggested that the application of principles of service user involvement such as those stated in the 1990 *NHS and Community Care Act* and in the 2002 and 2003 *National Minimum Standards* present a

particular challenge to service providers because of attitudes towards, and beliefs about people with dementia and because of communication difficulties. This reflects the way in which people with dementia are devalued by society and doubly disadvantaged because they are both older and have a mental health problem (Benbow and Reynolds, 2000; Graham, 2003).

Negative behaviours and beliefs at the level of the professional or the organisation can also impede empowering practice and disempower people with dementia at an individual level, by adversely impacting on their abilities, self-esteem and self-belief. Kitwood's conceptualisation of 'malignant social psychology' was used to exemplify this earlier in the thesis. For example, family members and professionals sometimes try and do too much for people with dementia, over-accommodating them and therefore disempowering them as individuals, by fostering dependence and decreasing the skills that they have (Kitwood, 1990; Adams and Clarke, 1999). Adams and Clarke (1999) suggest that people with dementia are frequently infantilised, by being treated and spoken to like small children which may result in low self-esteem and self-worth.

Goldsmith (1996) argues that professional practices and society more generally decrease the self-esteem and dignity of people with dementia by treating them like objects and refusing to listen to their voices. He illustrates the situation and attitudes within society by using a concept of a pyramid (Goldsmith, 1994). The top layer consists of professionals; beneath them are various other people and right at the bottom are people with dementia. He suggests one reason for this is the problem of communicating with people with dementia, as people do not know how to relate to or engage with them, whereas Proctor (2001) has suggested that there are power differences between people with dementia and their carers which need to be addressed, as these are bound to affect the efforts of caregivers to listen to the experiences of people with dementia. Additionally, because of the memory and communication problems that people with dementia experience, there has been a tendency to perceive them as less than human and their experiences, views and rights to choose have not been recognised (Kitwood, 1997). Such views are embedded within the traditional biomedical model of dementia, where psychosocial aspects of care have been marginalised and the focus has mainly been upon physical care, meeting basic needs and controlling problem behaviours with the use of drugs (Kitwood and Benson,

1995). Jones (1998) discusses service providers' denial of older people's voices, because of the assumption that older people are incompetent and incapable of making their own choices and decisions. Society has largely ignored the views of older people with mental health problems and has disempowered them.

Although there are now an increasing number of studies being carried out which include the perspectives of people with dementia, little such research has been conducted in the past (Proctor, 2001; Gilmour & Huntington, 2005). Disempowering practices and attitudes held by professionals suggest that people with dementia are unable to participate in identifying how they experience care services. Many presume that it is not possible to elicit accurate, reliable information from the person with dementia, because of cognitive impairment (Corner, 2002). A number of studies have avoided interviewing people with dementia altogether, for instance, Mozley et al (1999) describe studies such as that of Bland et al (1992), where people without dementia have been substituted for others with dementia. A number of studies have used the Mini-Mental-State Examination (MMSE) to exclude people with moderate to severe dementia (Reed & Gilleard, 1992). It has been argued that because there are so many receptive and expressive language difficulties and problems with memory, too many prompts have to be used in an interview and an unreliable picture of services is likely to be obtained (Brooker, 1998). Sarvimaki (1999) also argues the inappropriateness of standard structured interviews, suggesting that observational methods and informal interviews and discussions are more appropriate, although the risk of misinterpretation still exists. Most information about the experiences of people with dementia has been sought from carers rather than from people with dementia themselves (Stalker, 1999), often because the possibilities of obtaining useful feedback from people with dementia is discounted (Bamford, 1998).

However in recent years these views have been challenged and the feasibility of eliciting views and opinions from people with dementia, of involving them in decisions about their care and of promoting independence has been increasingly recognised. It has been suggested that people with dementia do possess the skills and abilities necessary to be empowered as individuals. Kitwood (1993) and others have argued that despite the cognitive impairment, personhood survives and a sense of self is retained even into the very end stages of dementia; there may be problems with memory, but the essential humanity of

the person still remains, since people with dementia still have feelings, imagination, will, preferences and drives (Cohen and Eisendorfer, 1986, cited in Downs, 1997). It has been argued that the public self is lost mainly through the way other people treat the person with dementia (Sabat and Harre, 1992) and survival of personhood is dependent on attitudes towards people with dementia and the treatment of them as people (Crisp, 1999).

The rights of the person with dementia to information and support are being increasingly acknowledged (Downs, 1997), for example with regard to sharing their diagnosis with them and seeking their consent. It is more widely acknowledged that being diagnosed with dementia does not necessarily imply incompetence and that if a person with dementia is unable to perform a particular task or tasks, it should not be assumed that they can not make any decisions and choices for themselves (Dubler, 1985; cited in Downs, 1997, p.601). Wells and Dawson (2000) suggest that people with dementia are able to do more for themselves than is sometimes realised and their review of several studies demonstrates that individuals with dementia retain certain abilities. They suggest that carers could promote these, thus allowing the person to function to their highest potential and have constructed an Abilities Assessment Instrument (AAI), to help carers identify which abilities remain. Bairns et al (2003) have devised a similar instrument called the 'Functional Behaviour Profile' (FBP), which seeks to identify the strengths of the person with dementia in order to plan strategies to maximise their abilities.

Marshall (1992) also argues that people with dementia could be more independent than is realised if the environment and people around them were more conducive towards this. For instance in an article about promoting mealtime independence (1992), she suggests that basic interventions such as ensuring that the table and chair are at the correct height, that utensils are appropriate and positioned properly, offering occasional prompts and praise and some supervision could help to maintain independence. More recently (1998, 2000, 2002) she suggests that changing environmental design and making use of available technology can promote independence by compensating for disabilities. There are devices available to assist with choice, safety and with memory and communication difficulties, which could be incorporated into individual care plans and serve to increase independence.

(3.6) The relatives of people with dementia

The relatives of people with dementia have been more empowered than people with dementia, in terms of participation in research and opportunity for involvement. This perhaps is to be expected given that relatives are less likely to be subjected to the same prejudice and discrimination by professionals and the wider society that people with dementia experience because of their mental health problems and old age. In contrast to the lack of research which incorporates the views of people with dementia, there is a substantial body of existing research which explores the views, feelings and perspectives of informal carers of people with dementia. Studies by Zarit et al (1998), Jootun and McGhee (1998) and Kosmala and Kloszewka (2004) have incorporated this approach. The majority of the literature focuses on the heavy physical and psychological burdens that the relatives of people with dementia endure (Wood, 1999). Burden has been defined by Zarit (1986, p.261) as *“the extent to which caregivers perceive their emotional or physical health, social life, and their financial status as suffering as a result of caring for their relative.”* ‘Psychological burden’ refers to *“carers’ emotional reaction and perception of strain”* (Adams, 1996, p.704) and includes loss, low morale, anxiety, depression, burnout and mental illness, whereas ‘physical burden’ refers to *“the practical support, physical health effects and daily routine changes”* (Wood, 1999, p.41). The levels of burden are thought to differ according to factors such as personal characteristics (Monahan, 1995), the relationship between the person with dementia and their carer (Daire, 2004; Jerrom et al, 1993), the coping strategies employed (Almberg et al, 1997; Norman, 2004) and the levels of informal and also formal support received. These might include day centres, individual interventions such as counselling and group interventions such as support groups and educational support (Curran et al, 1995; Davis, 1996; Mittleman, 1996, Coon et al, 2003; Brodarty and Gresham, 1989; Jarott, 2005).

Legislation exists which focuses on empowering informal carers, by requiring their individual support needs are addressed and they are enabled to live as full a life as possible. *The NHS and Community Care Act* (1990), the *Carers (Recognition and Services) Act* (DoH, 1995), ‘*Caring for Carers*’ (the National Carers Framework, DoH, 1999) and more recently the *Carers and Disabled Children’s Act 2000* and *Carers (Equal Opportunities) Act 2004* combined policy claim to address these issues. Legislation and policies state that

carers are eligible for and should be informed of their right to an assessment of their needs. The importance of the participation of informal carers in the planning and provision of care for people with dementia is also being increasingly recognised (National Service Framework for Older People, 2001). Clarke (1995) argues that relatives know the person before the dementia, their likes, dislikes etc and this knowledge can be used to develop services which value the individual and minimise the intrusiveness of the dementia.

But how far these strategies have been put into practice has been challenged (Wood, 1999; Teel & Carson, 2003). Jootun and McGhee (1998) consider the government's lack of commitment, demonstrated by their strategy for resourcing and supporting informal carers in the community. They argue that for choices to be given to each person and to ensure that carers receive the support that they need, the government needs to recognise the needs of informal carers and adequate resourcing is required. According to them, many carers are at breaking point, they have no one to turn to and warn of the detrimental affects of leaving them to cope without adequate support. They argue that lack of support impacts on the quality of life of both people with dementia and their relatives and that if carers are under extreme stress, situations of abuse are more likely to occur. Various policies such as the national strategy '*Caring for Carers,*' have been criticised, as according to Wood (1999) this lacks the direction and detail required to ensure improved liaisons between professionals and organisations involved in supporting carers and in relation to extending advocacy schemes and improving carer access to services. There is also evidence to suggest that carers do not feel like partners in care planning and provision as is required by government policies, but more as a resource to be utilised. This relates to previous discussion about the exploitation of informal carers, who are sometimes left to care, with very little support, help, influence or say, which does not fit within an empowerment model (Barnes and Warren, 1996). Gillies (1997, p.22) who interviewed informal carers about care provision reports that some carers felt they were "*at the mercy*" of service providers, rather than partners with them.

(3.7) Feasibility of eliciting views of people with dementia

Many people have now demonstrated the feasibility of talking to people with dementia about their experiences, which suggests that they may possess the cognitive and

communication skills necessary to be empowered at an individual level. Goldsmith (1996) argues that communication with people with dementia is possible, providing the will to communicate is there as well as the relevant skills and techniques.

Pratt (2002) and Reid (2001) successfully interviewed people with dementia and found this useful for exploring feelings and issues in depth. In addition, Moriarty and Webb (1997) spoke to people with dementia about living in a nursing home and found that participants articulated strong opinions clearly and consistently across time. Views have been elicited from people with advanced dementia, for example, Mozley et al (1999) and Ostwald (2002) obtained information from individuals who were significantly cognitively impaired, scoring below the normal cut off point of 17 on the MMSE. It has been suggested that certain methods can be particularly useful when talking to people with dementia (Tappen et al, 1997), for example, there has been an interest in the language of people with dementia. It has been suggested that analysis of talk which initially appears senseless, may uncover meaningful stories, metaphors and symbols which communicate experiences, feelings and emotions (Killick, 2005; Cheston, 1996; Crisp, 1995). These issues are developed further in chapter four.

Information has been sought from people with dementia about experiences of their illness and the coping mechanisms they employ to deal with it (Keady and Nolan, 1995; Gillies, 2000; Ostwald, 2002; Clare, 2003; Gilmour & Huntington, 2005). Although these studies focus predominately on people in the early stages of dementia and exclude people with moderate and severe dementia, there is much which can be learned. Participants described problems with memory, with communication, of feeling disorientated, frustrated, angry, foolish and frightened. Bahro et al (1995) found, from consultations with people with dementia, that individuals use a range of defence mechanisms to cope with the psychological threats of Alzheimer's and that partial or complete denial is used by most. Clare (2003), in a study exploring coping strategies employed by individuals with dementia, found two types. The first was 'self-maintaining' coping, which involved individuals attempting to normalise their situation and minimise any difficulties. The second was 'self-adjusting' coping, where individuals confronted their difficulties and attempted to come to terms with or accept their illness. Additionally, Keady and Nolan (1995) conducted interviews with people with early onset dementia and identified three

types of coping strategy. The first was managing the situation through taking direct action, by using lists and memory aids. The second related to managing the meaning of the situation by creating an alternative perception of events and the third involved managing the symptoms of stress. Based on these interviews they developed an instrument called the 'Index for Managing Memory Loss' (IMMEL), that lists the strategies employed and can be used to assess these. However, there is still a need for more research in this area, especially that which incorporates the perspectives of people with more advanced dementia, with a view to empowering them at an individual level. Although research has demonstrated the feasibility of eliciting views from this group of people (Tappen et al, 1997; Mozley et al, 1999), this perspective is lacking.

Studies eliciting views of people with dementia on care provision have also been undertaken, but these are few and relatively small scale, especially those which explore the impact of care provision on the quality of life of people with dementia. Studies again largely exclude those with more advanced dementia. Among the few studies that have been carried out is Innes et al's study (2003) that took into account the views of people with early stage dementia living in rural areas, on the types of care and support services they needed. They found that many participants were able to offer an opinion and respondents expressed a preference for services which encouraged a social life, provided stimulation, met their needs, provided 'loving care,' and which made them feel 'connected.' Coombes et al (2004) elicited positive views from three individuals with early onset dementia about a day care service and Heiser (2003) who explored the views of six people with dementia about the home care services they received, found that individuals valued companionship, good manners, independence, continuity in care and being able to trust their carer. Sutton and Fincham (1990, cited in Goldsmith, 1996) interviewed people in the early and middle stages of dementia about how they perceived the respite care services they received, using an open-ended, person-centred approach. They found that all subjects preferred to be in their own homes and that social aspects of care, such as activities were more important to them than physical aspects. It was also significant that people with dementia were able to provide very rich accounts of their experiences.

People with dementia, such as Ann Holden, Richard Taylor, Christine Bryden, a top civil servant in Australia and Robert Davis, a minister, have written accounts of their

experiences (Davis, 1993; Bryden, 2005; Taylor, 2005, Holden, 2005) and non-verbal methods have been developed for use with people with little or no speech, in order to allow them to indicate their preferences. Likert scale faces have been used successfully with people with learning difficulties, but these also have the potential to help people with dementia to express how they feel, for example, about different aspects of care provision (Stalker et al, 1999). Using pictures and objects has been shown to be useful when eliciting views from people with dementia and especially for stimulating conversation and discussion (Allan, 2000). Hopper et al (1998) have also discussed the benefits of using these, suggesting that having these present when conversing with people with dementia can decrease demands on memory.

Observational methods can be useful when seeking to learn how the person with dementia feels, or what their wishes are. For example, using a video camera (Knight, 2005) or observational schedules like Lawton's Affect Rating Scale, which involves direct observation of facial expression, body movements and other cues and Dementia Care Mapping (Kitwood and Bredin, 1993), which measures levels of activity and wellbeing of people with dementia (Kitwood and Bredin, 1992). The latter has been used with the intention of increasing empowering practice (Martin and Younger, 2000) and quality of care (Brooker et al, 1998) in care settings. Non-verbal communication is considered to be especially important in dementia care (Downs, 1997, Killick and Allan, 2001), particularly when verbal communication becomes difficult (Armstrong and Wright, 2002). Asplund et al (1991) argue that people with dementia are not so easily able to conceal their feelings or hide non-verbal language which makes it easier to read. A number of studies have incorporated this approach, for example, Jansson et al (1993) explored interactions between caregivers and patients in the terminal stages of Alzheimer's disease. From observing facial expressions of patients, they found it was possible to see them as capable of having and communicating their experiences to caregivers. Asplund et al (1991) studied facial expressions of people with severe dementia of the Alzheimer's type under unpleasant and pleasant stimulus conditions with the use of a facial action coding system and although they did not see any complex facial expressions, there was an increase in the number of facial movements, especially under the unpleasant stimulus condition. Based on observations of mood and behaviour, Curran (1996) explored how people with dementia felt about a day

care centre. She felt it was important to explore the therapeutic potential of day care for people with dementia which had scarcely been explored.

In conclusion, the concept of 'user empowerment' within mental health services is an important one. The extent to which it has been put into practice however, particularly within services for people with dementia, is open to question and there are several issues and problems that need to be addressed. The feasibility of empowering people with dementia is now being increasingly recognised. Recently, more attention has been given to their perspectives (Keady & Nolan, 1995; Phinney, 1998; Coombes, Colligan & Keenes, 2004) and innovative methods of communication have been developed. However there is room for further development in this area. There is a particular need to explore the impact of care provision on the quality of life of people with dementia and a need for further research that incorporates the views and perspectives of people with moderate and severe dementia on their experiences of their illness and care provision. Although this has been demonstrated to be feasible, to date, most research has focussed on those people in their earlier stages, excluding those with more advanced dementia. The relatives of people with dementia as service users have perhaps been empowered somewhat more than people with dementia, however it has been suggested that government strategies relating to the empowerment of informal carers are not always put into practice, because of a lack of commitment and resources.

4 AIMS, METHODS & SCOPE

This study, which was part of a larger investigation entitled: ‘Dementia of the Alzheimer’s Type: Communication Patterns and their Consequences for Effective Care,’ (Vass et al, 2002), is a collaborative study between Middlesex University and Jewish Care. All research was carried out within Jewish Care residential and day care settings, by a research team at Middlesex University. Jewish Care is a health and social care charity for the Jewish community, that includes the provision of care and support for people with dementia. This organisation was selected and approached for a number of reasons which included its existing relationship with Middlesex University. In addition, quality of care is given high priority by Jewish Care and thus they were very keen to participate in a study involving evaluation and were open to suggestions for improvement. They also recognised the importance of including people with dementia in the study and the need to employ different data collection techniques. Thus, they granted permission for use of the methods employed in the study, some of which could be considered to be very invasive and to which there are numerous ethical considerations attached, as they felt comfortable that the research team were able to negotiate these ethical issues. The project was funded by the Community Fund (previously the National Lottery Charities Board).

(4.1) Scope

The research was carried out exclusively within Jewish Care settings and all participating subjects were of Jewish origin, but it was anticipated that findings would be applicable to other settings and groups of people. It could be argued that the experience of dementia is similar whether the individual is Jewish or of another culture. With the exception of religious and cultural factors, many of the needs and values of Jewish people with dementia relating to quality of care will also be similar to those of non-Jewish people. It is therefore considered that the results of this study have relevance to other non-Jewish people with dementia, in other settings.

(4.2) Research approach

The study employed a qualitative approach, using methods of data collection and analysis that were of a qualitative nature. Qualitative research usually takes the form of words rather than numbers and is naturalistic in nature (Daniel and Huberman, 1994). Data collection techniques include participant observation, semi-structured and unstructured observation, semi-structured and in-depth interviews, life histories, focus groups and the content analysis of documents (Blaikie, 2000). Several of these methods of data collection were used in this study.

This study adopted an ethnographic approach, which underpinned and informed the methods employed. Ethnography is '*the art and science of describing a group or culture*' (Fetterman, 1989, p.11). It is about understanding another way of life by observing, listening and describing experiences, feelings and behaviour in detail (Neuman, 2003). It is about trying to understand another world from the perspectives of those who inhabit it. This study of ethnography drew on principles of the grounded theory method, as it involved producing descriptions and explanations of phenomena and developing theories in conjunction with data collection (Hammersley and Atkinson, 1995). It was considered that an ethnographic approach informed by the principles of grounded theory would be particularly appropriate for this study, which set out to explore, describe and enhance understanding of a relatively unexplored area - the lives and experiences of people with dementia. Ethnographers employ a holistic approach, attempting to gather many kinds of data by using multiple methods, so as to create as whole a picture of people's lives as possible (Fetterman, 1989).

The study employed methods commonly used by ethnographers, for example, interviewing and participant observation, which are considered crucial in order to gain a rich and detailed understanding of people's lives. Triangulation (Campbell and Fiske, 1959), a technique which involves using and comparing data gathered from a number of methods, was also used. In ethnographic research, this is considered to be useful for a number of reasons, for example, to eliminate alternative explanations and prove a hypothesis, to test the quality of information given and obtain a more complete and detailed picture of events (Fetterman, 1989). It was thought that this approach would be appropriate for this study, as

an aim of the research was to examine the reliability of accounts of participants, in order to explore the possibilities of empowering people with dementia. It was thought this could be achieved by using multiple methods and comparing the different forms of data gathered. It was also intended that as accurate and as whole an account as possible of the experiences and lives of people with dementia and their relatives would be obtained and this could be achieved by using and comparing various methods to try to gain a more complete and real picture of events in day and residential settings. As is discussed in this chapter, two methods of triangulation were employed, that is, methodological triangulation which uses a number of different data collection techniques to explore the same issue, in the belief that the shortfalls of one method will be compensated for by the strengths of the other. In addition, data generated from different techniques can be compared and examined for consistency or contradiction. Investigator triangulation, which involves making use of more than one researcher instead of data collection technique, was also employed. This study was part of a wider project in which two researchers independently made observations and recorded events, perceptions and perspectives which could then be compared. The observational data were shared. As with methodological triangulation, it is anticipated that the strengths of one researcher will compensate for the weaknesses of the other and having more than one researcher will help to reduce individual bias. As is discussed, methods of analysis were also underpinned by an ethnographic approach.

(4.3) Research Design

Chapter three reviewed the literature in the area and identified gaps in the research, which are addressed by this study. The literature has demonstrated that empowering practice has not always been applied to people with mental health problems, particularly to older people, such as those with dementia. This extends to research, where although there are now an increasing number of studies being conducted, which seek to involve people with dementia, these have been scarce if not nonexistent in the past. There is a need for more research, which incorporates the perspectives of people in all different stages of dementia, but particularly of those individuals in the mid and later stages of the disease.

Concerns about the dependability of the views of people with dementia is one of the main reasons for excluding them from service evaluation and other initiatives. This study aimed

to explore the feasibility of eliciting accurate information from people in all stages of dementia and thus the possibilities of empowering them at an individual level. The study examined the feasibility of obtaining dependable views about quality of care within residential and day care settings. It focused particularly on issues of empowerment, for example, behaviours and attitudes of staff, levels of involvement or power held by individuals and levels of quality of life. Additionally, experiences of dementia were explored. The study itself aimed to be empowering for people with dementia by enabling them to exercise influence and control over their lives. All feedback from service users was to be fed back to Jewish Care with the understanding that they would incorporate the findings into their work practices. Therefore an empowerment approach to involvement, which would result in change, was to be employed. The intention was for carer training packages to be developed from findings of the project which when delivered would result in a higher quality of care and thus increase empowerment at a societal-inclusion level, by enhancing quality of life for people with dementia. It was hoped that involvement in the study would result in personal development for participants, or at least offer some personal benefits, for example, increased self-esteem and feelings of control and influence. The process of research also aimed to be empowering and ways in which this was achieved are detailed in this chapter.

This study was primarily focused on people with dementia, but included the relatives of people with dementia, because it was thought that the care and support of relatives may be directly interlinked with or affect that which was provided for people with dementia. Levels of empowerment and the nature of support received were examined. Issues explored included the provision of information for relatives, including information about dementia and services; emotional, practical and financial support available; informal support received from friends or relatives; and formal support such as counselling, relative support groups, home help and day centre support. The study also aimed to investigate the levels of participation of informal carers in the planning and provision of care for people with dementia. The importance of this is being increasingly recognised (Keady and Nolan, 1994; Clarke, 1999). Additionally the project examined how dementia affected the families of the individuals concerned and aimed to gain insight into how relatives felt people with dementia experienced their illness and care services and were affected by them. This was considered to be important as earlier studies have reported discrepancies between the views

of people with dementia and their family members. This study explored this issue which questions whether relatives can represent the views of people with dementia and other groups of people.

(4.3.1) The Aims of the Research

The aims of this study therefore, were as follows: The study firstly aimed to explore the possibilities of empowering people with dementia by eliciting reliable information from them about the services they received. A second aim was to explore experiences of both people with dementia and their relatives of dementia and the quality of care received, focusing particularly on issues of empowerment. A third aim was for involvement in the study to be empowering for participants.

The research questions were:

- 1) Is it possible to elicit accurate feelings, needs and views from people with dementia about the services they receive and thus empower them at an individual level?
- 2) What more can be learned about dementia and care services, particularly in relation to empowerment, when we elicit views directly from people with dementia?
- 3) What are relatives' experiences of dementia and care received and do they feel empowered?
- 4) To what extent are relatives' views congruent with those of people with dementia?

'Quality of care' was the aspect of care provision selected as a particular focus, for a number of reasons. Firstly, there is a lack of research evaluating quality of care for people with dementia and secondly, the level of quality of care received is an important component of empowerment at the societal-inclusion level. It was thought that examining the quality of services and examining whether these are person-centred, empowering, uphold the dignity, rights and meet the needs of people with dementia was of utmost importance.

(4.3.2) Quality of Care

The care standards which were detailed in chapter two highlighted a number of aspects of quality of care worth exploring in this study and these informed the interview guidelines for people with dementia and their relatives.

Firstly, it was considered important to examine relationships with staff, relatives or visitors and other residents or members. It appeared necessary to explore how individuals with dementia felt about the people they came into contact with, their levels of contact and interaction, whether this was positive, negative, empowering or disempowering. Issues of dignity were also explored, as people with dementia were asked whether they felt valued and respected. Questions relating to choice and independence were incorporated into interview guidelines, i.e those which explored the levels of control and influence individuals had over their lives. They examined whether people with dementia were able to make their own choices and decisions about food, activities, times for bathing, bedtimes and mealtimes and whether they were enabled to do as much for themselves as possible. The levels of information received by people with dementia and their relatives were examined. Questions addressed the extent to which people with dementia were given information about what was happening around them or adequate information to be able to make informed decisions and choices for themselves. The topic of privacy was also explored and issues such as the levels of privacy during personal care considered. Questions were asked about the physical environment, such as decoration, furniture and noise levels and feelings about complaining or voicing concerns were incorporated into interview guidelines to elicit whether people with dementia and their relatives felt comfortable to complain if something was not right.

(4.4) Sampling

Within both residential and day care phases of the project, participants were selected randomly, a technique not usually employed by ethnographic or qualitative researchers more generally. On reflection there may have been a better method, however at the time it was considered that random selection would be effective, since a non-biased sample would be obtained to include people in various stages of dementia, of different genders and from

different homes and centres. This method of sampling aimed to provide the diversity of subjects required and at the same time eliminate the possibility of any individual bias during selection. Using this method of sampling means that each individual has an equal chance of being selected, regardless of age, gender, home, centre or diagnosis and the selection of one subject is independent of the selection of any other (Burns, 2000). Thus, lists of people with dementia were obtained from all the homes and centres within the two settings and individuals numbered within each setting and put into a hat and the number of people required from residential and then day care extracted. From eleven residential and nursing homes, 28 people with dementia and their next of kin were selected for participation in the study. This approximated to 10% of all those people with a diagnosis of dementia in Jewish Care homes. From within ten day care centres, 16 members were selected, eight from five community centres¹ and a further eight from five special day care centres, again approximating to 10% of people with dementia within day care services. Next of kin were also included in the study. The data obtained within the residential and day care phases were sufficient. The sample size was not large, however there were a great deal of data collected for each individual, as each person was interviewed, observed and videotaped for prolonged periods. Had data not been saturated on collection from the planned samples, then further samples would have been selected to expand data collection until saturation had been reached.

Measures of the severity of dementia were not taken, however on the whole, those in day care centres were perceived to be in earlier stages of dementia than those in residential settings who were considered to have more severe dementia. These were subjective observations based on levels of communication and memory impairment observed among individuals in the two settings.

(4.5) Data Collection Techniques

When considering techniques to obtain views and feelings from people with dementia, I knew from my own experiences of interacting with people with dementia and from the literature that communication is possible. However, I was also aware that eliciting views

¹ Jewish Care has two types of day care centres: community day care centres, open to all Jewish people over the pensionable age and special day care centres, which are more specifically for people with dementia.

from people with dementia is not straightforward and that finding the techniques to support participants to make the most of their communication skills and abilities, in order to maximise empowerment at an individual level, would be a challenge. It has been suggested that in order to communicate effectively with people with dementia, less emphasis should be placed on traditional methods (Jacques, 1996) and I therefore considered it would be important to use and develop new methods.

I was particularly influenced by the work of Tom Kitwood (1996) who suggested six qualitative ways in which insight into the subjective world of people with dementia can be obtained. Firstly, through the accounts that have been written by people with dementia. Secondly, by very careful listening to what people say in some kind of interview or group context, while paying close attention to metaphor and verbal and non-verbal body language. Thirdly, observing what people with dementia say and do in the ordinary course of their life. Fourthly, consulting people who have undergone an illness with dementia-like features, and who are later able to report on what they have experienced. Fifthly, “through the use of our own poetic imagination,” which refers to expressing imaginatively, through poetry, what it may be like to have dementia after spending time interacting and communicating with individuals with dementia. Lastly, using role play, that is actually playing the part of someone who has dementia, and living it out in a simulated care environment.

In this study, the second method was employed, that is listening to what the person with dementia has to say in a semi-structured interview and the third method which involves observing what people with dementia say and do on a daily basis. These methods are crucial in ethnographic research when seeking to gain insight and knowledge about people’s lives. Through carrying out observations, the researcher participates and becomes immersed in the culture of the group of people under study and through this can gain a deeper understanding of their lives; and interviews are important to acquire an appreciation and knowledge of experiences, thoughts and perceptions. It was considered that these two methods in particular would be an effective means of gaining insight into the subjective world of individuals with dementia.

I anticipated that people with dementia may experience some difficulty in relation to understanding and responding to questions and therefore thought that offering assistance in the way of non-verbal methods, which could be used in conjunction with interview questions, may be useful to support individuals to communicate their views. Ethnographic work is flexible and seeks to find and use different techniques and methods to suit the needs of individual participants. Strategies employed to help individuals to communicate their feelings, facilitate discussion and maximise response are discussed in detail later in this chapter. It was thought that faces or pictures might help people with more advanced dementia express how they felt, assist them with recall or help to stimulate conversation. I also considered that it may be important to take account of non-verbal language, as this may provide additional insight into the views and feelings of people with dementia. Sensitivity to non-verbal language is an important element in ethnographic research and provides useful information to the researcher (Fetterman, 1989). It was thought it may be useful to record the interviews on video camera in order to pick up non-verbal cues and in addition and with participants' consent, a video camera was focused on individuals throughout the day and observations were made in diary form. The files notes of individuals with dementia were also examined, for information about care plans, Care Programme Approach meetings and reviews. Relatives were interviewed using a separate semi-structured interview guideline. The methods employed are discussed in more detail below.

(4.5.1) Interviewing People with Dementia

I believed that interviewing people with dementia and their relatives would be an effective way to explore feelings and experiences of dementia and care services in-depth. Interview guidelines were developed based on current legislation, i.e. the care standards, gaps in the literature, on previous research and on my own experiences of interacting with and talking to people with dementia – see appendices I and II. Questions focussed on the different aspects of quality of care and the general health of the individual, however the main intention was to address current gaps in research and take account of service user perspectives on dementia and on quality of care. It should be made clear that although the guidelines intended to elicit particular information, they were flexible. The intention was that interviews would be led by people with dementia and their relatives as far as possible.

An informal and conversational approach was adopted and rather than adhering to a strict schedule of questions, issues were allowed to emerge naturally from conversation. Typically, individuals would introduce the topics, which would be followed up by the researcher, a technique which aimed to be empowering for participants, by allowing them to influence and control the research process. Individuals were encouraged to decide and make their own decisions about the issues they wished to bring up, rather than being told what they had to talk about and when and they were able to talk at their own pace and in their own time. Generally, the guideline questions aimed to elicit information from people with dementia and their relatives about the home or centre attended and how staff, residents and any visitors were perceived. They aimed to explore what relationships with other people were like and how empowering or disempowering these were. They intended to elicit information about participation in activities and if they were enjoyed. Questions were asked about the levels of choice and independence and the extent to which people with dementia felt able to control and influence daily life and activities. The interview guidelines included questions about different categories of quality of care, such as relationships, choice, independence, privacy, dignity, complaining and health. They sought to find out how people with dementia and their next of kin felt about each of these different issues. Next of kin were asked for their opinions on care services for the person with dementia, but also about the levels of information and support they received and about their own levels of participation in service planning and provision. Their experiences of dementia were also elicited, in particular how they and their relatives were affected and how they coped with dementia. Questions aimed to address how relatives thought the person with dementia perceived services and these views were compared with comments of people with dementia.

The interview guidelines were adapted as necessary in each of the three different phases. In the day care phase it was not necessary to ask questions about certain aspects of routine and personal care, such as bathing and dressing and going to bed at night and levels of choice and satisfaction associated with these, as they were not relevant. However other questions needed to be included in the guideline such as those about transport which was not an issue in residential care. The questions were designed to be as non-threatening as possible, so as to minimise the possibility of distress or upset and ensure individuals felt as comfortable and as confident as possible, issues which are important for empowerment at an individual

level. For example, as none of the participants with dementia were aware of their diagnosis, questions which aimed to elicit information about experiences of dementia were very general. They were about health and memory and the term 'dementia' was not used. This was a slight concern as I thought perhaps unawareness of the diagnosis and omitting 'dementia' may impact on communication about the experience of dementia. However, I anticipated that it would still be possible to obtain information about the experience of dementia without using the label of dementia by making reference to and picking up on dementia related symptoms and associated feelings such as memory loss, confusion, fear and communication difficulties. The interview guidelines were piloted in each of the three phases and adapted accordingly. Questions were rephrased, removed and additional questions were inserted where necessary.

Measures taken to facilitate discussion with people with dementia and improve response

In order to maximise empowerment at an individual level, it was considered important to develop and use strategies which supported people with dementia to make the most of their communication skills and abilities and to feel as comfortable and confident as possible. Consistent with ethnographic research, an informal and flexible approach was employed. Broad, open-ended questions were used. I had found these types of questions to be most effective in my work with people with dementia and other mental health groups and in keeping with this, research has shown these types of questions to elicit longer and more meaningful responses. They allow the individual to give as much information as they are able and maintain self-esteem (Tappen et al, 1997). According to Tappen et al (1997), people with dementia became angry when asked for specific information which they could not remember, as it was a reminder of the problems they were experiencing and made them feel bad. It was also considered that recognising and focusing on salient themes which people with dementia introduced in interviews would be important. Tappen et al (1997) suggest that once this is achieved, verbal and non-verbal techniques, paraphrasing and summarising can help to maintain the conversation. It was thought that using this type of method would be empowering in the sense that it would allow individuals to exercise control over the interview.

In addition, I thought some individuals may have a preference for third-party approaches, which may help them to express their views and to feel more comfortable. This method involves asking the person with dementia to imagine they are thinking about someone else, such as a friend or relative, or showing them a picture of another person (a third party) and then asking them what that person might think, or what they might tell them about the home or day care centre. Allan (2000) found this approach to be helpful and suggests it may be particularly useful for people who find it difficult to answer direct questions about what they think. I also envisaged the use of pictures and scales as I thought these might stimulate discussion and help people with dementia answer questions. These are discussed later in this chapter.

I was fortunate in being able to draw on my previous experience of working with people with dementia and other mental health groups and also on suggestions of other practitioners and researchers in the field in preparing to interview people with dementia. Very importantly I drew upon counselling skills, learned in my previous work, which are very useful in any interaction and situation. These are commonly used by ethnographers and I felt they would be crucial when interviewing people with dementia and drew upon several specific strategies. Most importantly, I considered that the skill of listening would be vital. In any interaction it is essential to listen carefully to what is being said and allow sufficient space and time for thinking and speaking. I felt this would be particularly applicable to people with dementia, who may take more time than others to process information and come back with an answer. It would be important not to jump in to fill the gaps, but to allow and be comfortable with silences. In order to encourage the individual to speak, open up, feel comfortable and confident to talk about their feelings and build a rapport, it was considered necessary to be friendly, gentle, sincere and encouraging and show genuine interest in what was being said, through being actively attentive. This could be achieved through maintaining eye contact and responding by verbal and non-verbal means. I thought attending to non-verbal cues would be helpful as well, as non-verbal messages may provide additional information, substitute for non-verbal responses and convey true meanings. Therefore, it would be useful to observe appearance, facial expression, movements and gestures and look for accord between verbal and non-verbal communication.

I considered open questions which draw out more information and avoiding yes or no answers would be highly important, as would showing empathy with the individual and being non-judgemental. Paraphrasing, summarising and reflecting back feelings would also be necessary, as would trying to remain calm, even if I did not feel calm, which would help to relax the interviewee. It would be imperative to be non-confrontational and if the other person had a different point of view with which I did not agree, not to negate it but accept that is how they felt. I felt this would be especially important when talking to people with dementia because their beliefs may not fit with what I believed to be true, which may be a result of memory difficulty or their sense of time or orientation may be different. Additionally people with dementia may have more trouble with understanding and speaking than others, and it was therefore considered essential to speak clearly, slowly and simply, while respecting the individual and not patronising them and not treating them like a child. It was believed that touch may also be an important form of communication, perhaps to attract someone's attention or to comfort them when distressed. In addition, Goldsmith (1996) makes several recommendations which were taken into account. These include using short sentences which do not carry double meanings and if at all possible illustrating what you are saying by hand gestures and body language. It may be great effort for the individual to communicate, and Goldsmith suggests it may therefore be helpful to be complimentary in an adult way and important to show your pleasure when they succeed. He also recommends adapting to the pace and time scale of the person with dementia, taking account of environmental factors and studying non-verbal communication.

Making sense of what the person with dementia is saying

Trying to or being able to make sense of what people with dementia were saying in interviews was an obvious concern before beginning the fieldwork. Some people seem to be able to understand and attach value to what the person says, even if they are in the later stages of dementia. Crisp (1993, cited in Keegan, 1998) discusses the on-going ability of people with dementia to interact socially well into advanced stages of Alzheimer's. On the other hand, others have reported the speech and interactions of people with dementia as nonsensical, such as some of the relatives in this study.

My own view is that there are particular cues or ways of understanding what people with dementia are saying and again I drew on previous experience of working with people with dementia and on the existing literature in this area. It was important for me to develop my own communication skills, abilities and knowledge in order to facilitate communication and enhance empowerment at an individual level. For instance, I thought that careful listening to the words of people with dementia and paying attention to the context and non-verbal cues would be crucial.

When trying to interpret what the person with dementia was saying, I considered it would be important to take account of their past (Adams & Clarke, 1999). In my work within mental health, comments and actions of service users were much clearer in the light of their past experiences or actions. It was thought that remembering that the person with dementia's sense of time may be different to our own and finding the person's frame of reference may also be helpful. Crisp (1996) suggests this can be achieved by asking simple questions and listening, but she warns against imposing interpretations on what the person with dementia is saying. These suggestions and issues informed my ideas about interviewing people with dementia. In addition, it has been noted that people with dementia tend to move towards broader categories when they name or talk about things and knowing this may help with interpreting what they are saying, for example, 'dog' may perhaps mean 'dog-like' (Adams & Clarke, 1999). It was considered it would be useful to make links between words which appear inappropriate and those which are usually used. Keegan supports this idea, drawing on her experiences of communicating with Jean:

“At times Jean's speech contains what appear to be distortions of the words which she intends to use, neff means neck?, sestuary means necessary.” (Keegan, 1998, p.8)

Obviously, a difficulty with this approach is that it may not always be straightforward to establish what the 'right' word is or what the person means to say. This is to some extent open to interpretation.

It was also considered it would be important to focus on what the person was achieving rather than on errors that they were making, an approach which has been recommended by

others such as Crisp (1993, cited in Adams & Clarke, 1999). In Crisp's study (1993), in which people with dementia were asked to name an object, 65% of the 'wrong' responses had some sort of link or association with the object and she suggests that the functioning of the brain was not far from how it should be working, an important issue to remember when carrying out the fieldwork. In addition, it was thought that being too critical may affect the interviewer-interviewee relationship and hinder communication. It would also undoubtedly affect self-confidence which is important for empowerment at an individual level.

I also thought that it would be necessary to be aware of confabulation, which is common among people with dementia. Confabulation refers to people telling stories about themselves, in which past and present events and things that they did, heard about or simply imagined are all mixed together, but presented to us as true (Crisp, 1995). It was felt it would be essential not to completely disregard or negate what the person was saying, but to accept their reality and look for meanings in the stories. As Crisp (1995) suggests, stories may provide some insight into how the person with dementia feels about certain issues in the present, but perhaps they find it easier to express these feelings in terms of past or fictional events as these are easier to recall and talk about. Keegan (1998) proposes another function of confabulation, suggesting that people with dementia confabulate when they are trying to cover up memory loss or 'throw you off the scent.' She suggests that loss of memory, which results in disorientation in time, place and person can cause the person with dementia distress and I felt it would be important to be aware of and sensitive to this.

Participant/researcher relationship

The professional/service-user relationship was considered to be crucial. Involvement in this study aimed to be empowering for participants and it has been argued that empowerment is of limited value if it does not extend to relationships between professionals and service users (Greenwell, 1996). A period of up to one week was spent with each person, which enabled a rapport to be built between the researcher and person with dementia. It was deemed important to establish trust with participants, as it has been argued that this is integral when looking to develop positive and empowering relationships (Barnes & Warren, 1996). It was anticipated that a trusting relationship would enable individuals to feel more at ease, comfortable and confident in interview, which would help

to facilitate empowerment at an individual level. In addition, I anticipated that there may be some degree of denial among individuals about their illness, the problems they were experiencing and covering-up of problems, particularly to a stranger or outsider. It was hoped that by spending time with each participant, they would feel more able to open up and talk about their feelings than if they had not known the researcher at all.

In order to develop and maintain trust and confidence, a number of measures were taken. It was thought it would be important to listen, to be empathic and non-judgemental and to accept the emotional reality of the individual. Facilitating opportunities for control over the research process would also be important, for example the interview should include open-ended, broad questions and be as participant-led as possible. Brechin (1993; cited in Richardson, 1997) makes some useful suggestions which were taken into account. These include building friendships with individuals, promoting confidence by not making the person feel small, enabling them to make their own choices and decisions about methods and finding alternative ways to communicate if necessary, that is being prepared to compensate for disability. In addition, Richardson (1997) emphasises the importance of informality and avoiding jargon. It was considered that all of these issues could enhance self-esteem and trust and thus promote an empowering research environment. The importance of a reciprocal relationship or equal partnership has also been highlighted (Barnes and Warren, 1996) and it was considered this may be developed by forming friendships, building rapport with individuals and working with participants to identify the most effective methods, which might have included the use of pictures, scales, the video camera or involved conferring with individuals to establish the most suitable environment or most comfortable place to be interviewed. Some individuals may have felt less threatened or more comfortable with or without their family, or at certain times of the day or week. Factors such as noise levels, the presence of other people or the person's preference for being interviewed in their own room in the home or in the communal area would need to be taken into account. All of these measures were observed, in an attempt to equalise relationships between the researcher and participants, however it has been argued that some degree of inequality will always remain (Richardson, 1997). I felt the important issue would be to minimise this as far as possible.

In conclusion, a variety of methods and techniques can facilitate the process of communication and support empowerment. These include allowing individuals as much control and influence over the research process as possible; attempting to build equal and empowering relationships with participants; and finding ways to maximise communication between the researcher and participant. These factors informed the choice of data collection methods and were put into practice where possible in this study. An interview guideline was developed, to elicit information on experiences of dementia and on quality of care, which was designed to be non-threatening, made use of broad-open ended questions, third party approaches, pictures and scales. A flexible approach was employed, and the interview format, style and the environment were adapted to the needs of individuals.

(4.5.2) Using non-verbal methods to elicit views of people with dementia

Pictures and scales

Because of the potential difficulty with eliciting information through interviews, a variety of alternative or non-verbal methods were available which could be used in conjunction with the interview questions to help people with dementia to communicate their views. Ethnographic research is flexible and adaptable and caters to the needs of individuals. The process of method selection aimed to be empowering for the person with dementia, as much as possible. It was intended that individuals with dementia would have influence and control, by being able to make their own choices about the methods they wanted to use. The methods were to be presented to interviewees at the start of interview, or introduced at some appropriate point later. If individuals had difficulty understanding and responding to questions, they could then decide whether or not they wanted to use them and which they would prefer. For example, faces were to be available to help people with dementia express how they felt about different issues. These have been used previously with people with learning disabilities who have communication difficulties (Stalker et al, 1999) and also with people with dementia, e.g. the Dementia Mood Picture Test (Tappen and Barry, 1995).

The faces that were used in this project were adapted from the 'Delighted-Terrible Faces (D-T) Scale' (Andrew and Withey, 1974, 1976; cited in Bowling, 1997). This scale consists of seven faces, all of which have different expressions, ranging from delighted to

terrible as the name suggests. In this project, only three of the faces were used, that is: a happy face, a sad face and a neutral face. The reasoning behind this was that people with dementia and those with visual impairment may find it difficult to distinguish between very subtle changes in expression and that to use three distinct faces would be more effective. These faces were used in conjunction with the interview questions. If a question asked how the individual felt about a particular aspect of the service they received, and the person with dementia was not able to articulate an answer, they could simply choose to point to the face which best described the way that they felt. It was an option that was available which would put less demand on the person's memory and verbal communication skills. It was anticipated that faces may be used by people with moderate or severe dementia but probably not by those with early onset dementia, because of their better verbal skills.

In addition, pictures of food, decoration and activities were available for use to help stimulate and aid discussion about care provision. These were used in conjunction with interview questions, as a substitute for questions or not at all, depending on the severity of the dementia and on individual preferences. It was thought these would be useful to stimulate discussion. Others have demonstrated the benefits of using pictures to enhance communication, e.g. Allan (2002) and Spector et al (2002). Bourgeois et al (1990) studied the effect on conversation ability of people with dementia, when providing stimulus materials in the form of wallets with photos of events and persons the individual could not remember. They found that subjects made significantly more factual statements and fewer ambiguous ones. Keegan (1998) found having pictures relating to the subject discussed helpful when talking to a person with dementia about issues such as gardening. Bamford (1998) has also reported the usefulness of stimulus materials like photographs for talking with people with dementia about things that are not present or going on at the moment. It was thought that pictures would be helpful when eliciting views from people with dementia as they would help with the recall of certain events and issues which individuals may not have been able to remember otherwise. Hopper et al (1998) suggest that despite memory difficulties, individuals with dementia can often recognise events and places that they cannot actively recall, for example, a person with dementia may be unable to recall a recent event such as a family reunion, but when presented with a picture of the event, the person may recognise and be able to converse about it. Having a stimulus present in conversation may decrease demands on memory and provides a shared context for meaningful

communication. Recognition of items or words is much easier than having to actively recall them, and applies to everybody, but increases with age (Stuart-Hamilton, 1994).

Videotaping interviews

After consultation and agreement from individuals with dementia, interviews were to be videotaped and examined for non-verbal responses and communication during discussion and for accord between verbal and non-verbal responses. In chapter two, the ability of people with dementia to communicate non-verbally up until the very end stages of the illness was discussed. It was thought that paying close attention to the body language of people with dementia would be vital when eliciting their feelings and views, particularly from those who had lost many of their verbal skills. Non-Verbal Communication (NVC) plays a central part in human social behaviour; its functions are conscious or unconscious and include the expression of emotions, communication of interpersonal attitudes and accompanying and supporting speech (Argyle, 1991). NVC includes facial expression, gaze, gestures and other bodily movements, posture, bodily contact, spatial behaviour, clothes and other aspects of appearance, non-verbal vocalisations and smell. Each of these categories can be divided yet further, such as gaze which includes looking while listening, looking while talking, mutual gaze, length of glances, amount of eye-opening and pupil expansion. The face is probably the most expressive in terms of NVC. Emotions can be classified in terms of dimensions, from unpleasant to pleasant and according to level of arousal and they fall into types, such as happy, sad, surprise, anger, disgust, fear, interest, shame and less subtle ones such as amusement, boredom, impatience, pain and fatigue. These can be expressed by the mouth, eyebrows, skin colour, facial movement and also by position of the hands, posture and the tone, pitch, speed, volume and rhythm of speech or voice. Signals of liking may depend on proximity, such as leaning forward, more direct orientation, more gaze, more smiling, gestures, head nods, lively movements, open arms, higher pitch and more self-disclosure. It was thought that observing such communication would provide interesting and useful insights into how people with dementia felt about various issues and people in their day to day lives.

Observing and videotaping the day-to-day lives of people with dementia

Method triangulation which is commonly used in ethnographic research, was employed in order to enhance credibility and dependability during data collection. Besides being interviewed, a video camera was used to record the day-to-day activities and the lives of selected people with dementia and observations in diary form were also made on a day-to-day basis. Each person was videotaped for five days (07.00 – 19.00) in the residential phase, with one early morning and one late evening session and they were videotaped for two days in the day care phase, from the time they arrived at the centre to the time that they left. The filming times selected were convenient for participants and they corresponded with the times they were at the day centre and in the communal areas of the home.

Videotaping can be extremely helpful in ethnographic research, when seeking to explore the lives and experiences of people. Couchman (1995) and Latvala et al (2000) discuss the usefulness of this method, for example, the behaviour of the person with dementia throughout the interview can be recorded and analysed repeatedly for the extraction of information, as sometimes it occurs so quickly that it may be missed by an observer. The technique also provides a medium for identifying and analysing every aspect of human behaviour, including the evaluation of gestures and facial expressions. However, this method has not escaped criticism. For instance, it has been pointed out that using a video camera could be very disconcerting to the person or persons being filmed and their recorded behaviour could be unnatural or artificial and the results may not reflect reality. In addition, there is a risk of tunnel vision (Fetterman, 1989), in that the camera may focus on a particular individual, behaviour or event to the exclusion of other things going on, thus producing an incomplete picture of events and little indication of the context in which things are happening. However, it was considered that the advantages of using a camera outweighed the drawbacks and to address the latter, recordings of the first day were discarded, after which it was thought that individuals would have habituated to the camera. Cameras were fixed in brackets at the top of the wall, near the ceiling, so their presence was less intrusive and the angle of the camera was altered at intervals to focus on different areas of the room, so as to gain an idea of events and interactions happening elsewhere. It was anticipated this information would be useful, as these wider events and issues may have

impacted directly or indirectly on the experiences of the individual(s) being filmed, help with interpretation and provide a more holistic picture of what was happening.

Observations, which are also important in ethnographic research (Hammersley & Atkinson, 1995), were made and recorded in diary form. These were carried out during the hours of 7.00 to 19.00 in the residential phase and for the two days in the day care phase. Observational notes were particularly useful when a camera was not present or was turned off for some reason. This happened because the researcher was not able to reach the camera to change the tape because there were people obstructing the way and asking them to move would have disturbed an activity. They may even have refused to move, which was their prerogative. Staff, relatives or service users may have requested the camera be switched off for a period of time or an activity or events may have taken place in an area where there was no camera, such as another room, corridor or reception area. In these instances, a smaller handheld-digital camera was occasionally used to record events and activities.

The video and observational data were cross-referenced with the interviews of people with dementia and their relatives in order to support the dependability of interpretation. In keeping with ethnographic research, the data yielded from both of these methods were compared to establish similarities and discrepancies, and to explore whether the comments of people with dementia and next of kin were supported by observational and video data. It could be argued that it is disempowering for participants to use another method to establish the reliability of their views and opinions, as this devalues or questions the credibility of their accounts. However, subject to the results of the study, it was hoped that this method would actually end in greater empowerment of individuals with dementia, in demonstrating to others the extent to which views of this group of people can be reliable. It was hoped that more empowering practices, which could benefit individuals with dementia collectively, would be initiated and developed as a result of this study. Video and observational data also provided supplementary information, such as details about aspects of care, which had been forgotten and feelings about certain events and data on organisational matters, which may have impacted on people's experiences. Therefore one method compensated for the other. It was thought that video and observational data would provide additional insight into the type of interactions people with dementia had with

others, the levels of contact they had with staff, fellow residents or members and visitors, and insight into their routine, levels of choice, independence and privacy. Combining the two methods of interviewing and filming or observing would result in a more holistic picture of what life was like for people with dementia and how they may have felt about the services they received. Researcher triangulation was also used as two observers independently recorded events and interactions and these were written up and discussed on a regular basis throughout the research process. Observations could be compared and examined for similarities and discrepancies and reasons for any differences established, i.e. perhaps one person was missing important issues or they had a different perspective on what was happening. Discussion around the latter enabled a more balanced and objective end account to be produced by combining and integrating the accounts of the two researchers. This method reduced possibilities of individual bias. Other ways in which reliability was enhanced are discussed below.

Examination of documentary evidence

In ethnographic research, documentary evidence can be a very valuable source of information (Silverman, 1993; Hammersley & Atkinson, 1995). Various documents, such as care plans and files notes of members and residents were inspected and details about Care Programme Approach reviews, daily care and events were recorded.

(4.6) Credibility and Dependability

As mentioned earlier, 'triangulation' was used to enhance credibility and dependability during data collection, as two researchers independently recorded events. In addition, video and observational data were compared with interview data in order to support the reliability of the accounts of participants. This perhaps makes a questionable assumption that the video and observational data were reliable indicators of what went on. Since this data were so pivotal to results of the study, further checks were carried out to enhance the dependability of these and also other forms of data collected. The following methods used have been recommended by Robson (2002) and included trying not to be biased throughout the research process, by taking in all the available information, rather than being selective. What was observed and said in interviews and document information were recorded

verbatim. The exact words, the mood and the context were noted. I also tried to remain open minded throughout the research process and open to any unexpected findings. Findings were shared with colleagues on a regular basis who were able to offer alternative explanations and suggestions for data collection. Rather than just recording information, I interpreted it as I went along and in this way any contradictions came to the surface and requirements for further evidence, which could be obtained then, as later it may have been too late. For example, while conducting interviews, it was important to interpret what was said as the interview progressed so that I could frame subsequent and follow-up questions appropriately. Had I not done this, some important points which required further exploration may have been missed or overlooked and later it may have been too late to go back and acquire the information. Similarly, if an individual with dementia perhaps commented on the lack of stimulation in her residential home, I was able, while carrying out observations in this care setting, to give particular attention to what went on the way of activity and interaction and check files notes and careplans to find out what the home aimed to provide and so on. I could also explore this issue with other individuals during interview to find out whether other people had similar or differing views and feelings. Again, had I attended to this issue after data collection had finished, it may have been too late and certainly much more difficult to obtain this data.

With regard to video recording, the focus and position of the cameras were altered at intervals, so as to capture both individual interactions and communication and the broader picture. It was anticipated that this information would help with interpretation and prevent 'tunnel vision.' When the tape ended it was immediately replaced with another, so that events and interactions were not missed. If it was not possible to change the tape or record at a particular time, observational notes were taken to substitute for video recordings or use of a smaller hand-held camera was employed. Further information about measures taken to enhance credibility and dependability during analysis are discussed later in this chapter.

(4.7) Data Analysis

As described, data collected consisted of interview transcripts, detailed observational notes in diary form, video material and files notes. A qualitative approach to data analysis was required, since the data collected were of an ethnographic nature. This focused on

identifying patterns of thought and behaviour and on finding meanings in what was said and observed in order to enhance understanding and knowledge about the lives and experiences of people with dementia and their relatives. The analysis was an ongoing process, which began during data collection, as I became conscious of the themes, which were emerging from the different types of data. The iterative nature of qualitative research meant one interview informed another or shaped the focus of the observation and subsequently the analysis.

The computer-based ethnographic program, NUD*IST (Non-Numerical Unstructured Data Indexing, Searching and Theorising), which has been demonstrated to be useful for managing ethnographic data (Chambers, 2003), was used to organise, categorise and code the interviews, video data, observational data and document information, in order to start to be able to make sense of, understand and find and establish patterns and meanings in the accounts given by people with dementia and the observational and video material. The diaries, interviews and file notes were examined and information and data coded in appropriate categories, which are discussed below. Similarly three videotapes were randomly selected per individual participant in the residential phase and all those taken for each participant in day care, because there were fewer as individuals were only filmed for two days, rather than a week. These were viewed and relevant information indexed in the different categories, before comparisons were made.

There are several different methods of creating codes and categories. The approach employed in this study was adapted from the grounded theory method (Glaser & Strauss, 1967). This method, which is commonly adopted by qualitative researchers, requires that codes are created only after data have been collected, so that theory emerges from the data (Lampard, 2002). In keeping with this method, my approach allowed for data to emerge but it is important to acknowledge that my professional experience and the literature research meant I did not enter the research with a completely blank slate. I had an idea of some of the issues, which needed to be explored before data collection began and they informed the research and interview questions formulated and enabled me to create a provisional list of codes before data collection. However I could not anticipate the extent to which people were able to articulate their experiences or feelings or what these might be and therefore the codes were only considered following data collection. My framework

was flexible enough to allow other issues to shape the research agenda and codes were introduced, adapted and revised depending on the nature of the issues which became apparent on reading the transcripts.

The data generated from interviews, observational diaries, video recordings and documents were indexed accordingly and narratives and observations were put into the appropriate categories. A priori codes and categories were based on the interview guidelines, which were informed by the research questions and on existing literature. These included broad categories such as relationships, choice, independence, privacy. As themes emerged from the data, new codes were derived to describe the experiences, feelings and meanings, which were expressed or demonstrated. Interview and observational data relating to people with dementia were identified separately to those of next of kin, so that they could be compared. Data collected within residential and day care settings were also recorded separately, so it was easy to explore what had been said and observed about each different setting and comparisons across services could be made.

Categories which were common to both residential and day care indexing systems included 'eliciting views of people with dementia,' since there was an attempt to obtain information from individuals in both settings. Here the extent to which the views of individuals with dementia were elicited, and issues relating to this, were recorded. Interview transcripts and video and observational data were examined. Attention was given to how things were said, to what was being communicated, to possible meanings behind this and whether it was supported by video and observational data. Analytic sub-categories included denial, confabulation, non-verbal cues and levels of consistency or inconsistency between verbal and non-verbal responses and between video and observational data and the interview data. Other categories included meanings behind what was being said, links between words, such as perhaps a similar sounding word or a word with a similar meaning to the appropriate one was used, the usefulness of third-party approaches and pictures and scales.

Other categories related to perceptions and observations of quality of care. For instance, 'choice' was a category common to both residential and day care indexing systems. Comments of people with dementia relating to this issue, along with all diary observations and video data, were recorded. Several sub categories of this larger one were created, such

as choices offered at mealtimes, bedtimes, with regard to activity and all comments and observations were encoded in these. The intention was to explore the levels of influence and control that individuals had over their lives, for example, were residents and members able to exercise choice in relation to the time they wanted to eat or what they wanted to eat, when they wanted to go to bed or go to the toilet and so on. This information was elicited from interview transcripts and observational and video data and recorded in this category and it was then possible to explore what people with dementia had said about the choices available to them, in relation to different issues and to compare this with the observational and video data. Comments, observational and video data relating to issues such as whether people with dementia were encouraged to do things for themselves and to make their own choices and decisions were recorded under the heading of 'independence.'

The category called 'relationships of people with dementia' had several sub categories, such as relationships with visitors, staff and with other residents and all data relating to these were recorded. Further sub categories considered the length and type of interaction and whether this was task based or more socially orientated. The levels of stimulation provided for people with dementia were documented, which recounted whether individuals were left sitting for long periods of time or whether there was much activity provided. Under the category called 'privacy,' comments and observations relating to the amount of privacy offered or available to the person with dementia were noted during personal care procedures and whether individuals were able to go somewhere to be alone if they wished. The category called 'dignity' included responses, observational and video data relating to whether people with dementia felt respected by others and the category called 'complaints' noted whether they felt comfortable or uncomfortable about complaining and their reasons for this. Aspects of the physical environment were also documented, such as the seating arrangements, the size of the room, the type of furniture, decoration and noise levels and how people with dementia felt about these.

The type and nature of verbal and non-verbal communication, reactions and responses of people with dementia within observational and video data were also examined. Levels of boredom, restlessness and also anti-social behaviour were documented in the relevant categories and possible triggers for these such as frustration, anger, fear and agitation were recorded. Similarly, pleasure, happiness, calmness or humour were noted and the periods

or times these feelings and reactions were displayed, whether they were in response to another person or to an event or activity.

As mentioned, relatives' comments were coded separately, so that they could easily be compared to the views of people with dementia and data could be scrutinised for discrepancies or similarities. Categories for relatives included how they felt about the service provided for the person with dementia. Several sub categories were created which corresponded with those created to encode comments of people with dementia about services they received. For example, sub categories called choice, independence and dignity were included. Another category related to how relatives felt the person with dementia perceived the services provided and similar sub categories were created such as those called complaints, dignity, choice, relationships and comments about these issues were recorded. Creating separate categories for relatives made it easy to compare their perceptions with those of people with dementia. Other categories related to relatives' experiences of dementia, and to the information and support received and comments on these issues were documented.

Credibility and dependability during analysis was enhanced by triangulating the data, that is, comparing or cross-referencing the interview data with the observational and video data and looking for similarities and discrepancies. Triangulation is fundamental to ethnographic research, as it helps to obtain a broader and more holistic picture of the situation or events and can help to determine and test the quality of the data obtained through any one method (Fetterman, 1989). Additionally, a small amount of quantification took place. Daniel and Huberman (1994) have listed a number of benefits of carrying out qualitative data analysis with the aid of numbers. They argue that the general drift of data can be seen more easily and rapidly by looking at the distribution of responses and additionally, counting can test for individual or researcher bias during the analysis of qualitative data. There is a tendency in qualitative analysis to remember particular informants or stories because they are well articulated, dramatic, sad or in some way memorable. Counting can help eliminate the potential for distortion.

Benefits of using NUD*IST

Computer Assisted Qualitative Data Analysis (CAQDAS) has been used since the mid 1980s (Fielding and Lee, 1991). There are a number of benefits of using computers in qualitative research. With a package like NUD*IST, the quantity of data can be handled much more efficiently than if using a manual method of analysis (Richards & Richards, 1994). There is often so much data to sort through and spreading it out on the floor and trying to make sense of it and analyse it in this way is not ideal. Qualitative data are typically unstructured and messy and a package like NUD*IST provides an efficient and flexible method of handling the data and organising it. It has a document system which can include online documents such as interviews and observations and also offline documents like pictures, a literature review or videos. Notes and memos can be attached to various documents and it has a separate index system which sets out the categories and themes identified in the project.

The categories may be arranged hierarchically in tree diagrams, with categories and sub-categories showing the linking of ideas and categories can easily be moved around from one place to another in a tree structured index system of thinking. There is no limit to the number of categories that can be used, so categorisation can be complex and refined. NUD*IST will also allow the researcher to switch back and forth between the coded material and the original documents, in order to enable tracking of the context in which something was said or happened. Thus use of such a package facilitates the handling of data from multiple sources. Additionally, using a package like NUD*IST can save much time, as computers are fast and flexible and data can be coded much more quickly than if they were to be coded manually. Much time is freed for thinking about the analysis. Using CAQDAS can also enhance the acceptability, credibility and respectability of the data analysis, as what was seen as a 'soft' methodology, where it was difficult to make any generalisations is boosted because a computer is being used. Transparency is also enhanced as systematic analysis is encouraged, so replicability is increased, and the path by which a particular analysis emerged can be traced (Fielding and Lee, 1991).

However, there are criticisms of using this approach, for instance, training is required in order to be able to use the package efficiently and it has been argued that access to this and to packages themselves may be difficult because of the costs. Although Fielding and Lee (1991) found that costs of such a package are not high and it could be argued that training is required to use any package, including that which is quantitative, such as SPSS. Another challenge to this approach is that perhaps the researcher may end up playing with the data and package, because it is so easy to use, rather than carrying out any meaningful analysis. More complex coding than could be carried out manually is manageable, therefore perhaps not much time will be saved (Fielding & Lee, 1991). Additionally it has been said that perhaps users may not realise the full potential of CAQDAS, so they waste time coding and doing little else with the data. Closeness to the data may also be compromised, as using a computer may discourage involvement and engagement with the data, so the analyst could skim the surface of very rich data (Fielding and Lee, 1991).

Personally, I did not feel that using a package like NUD*IST compromised my closeness to the data and I felt I was able to examine data in-depth. In order to code data it was necessary to go through each interview transcript or set of observational, video or file notes thoroughly. Categories were not prescribed, but I was able to create them and these could have been as complex as I wished them to be. Additionally, after data had been coded, it was very easy to obtain access to the original document, as NUD*IST allows interaction between the indexing systems and the original data sources. Therefore if I wanted more information about the coded comments, observational, video and file data or wanted to examine the context more closely, it was easy to obtain/do this. I found NUD*IST to be of great value, as the package helped me to organise the data very quickly and efficiently, in a way that would have been much more difficult and time consuming to do manually.

(4.8) Role of the researcher and reflexivity

My role as researcher was to develop the research tools, to interview and talk to each individual and explore their experiences of dementia and views about care provision, using the chosen or preferred methods of communication. Importantly and at a professional/organisational level of empowerment, it was necessary for me to support individuals to empower themselves at an individual level. When collecting data, I needed

to use strategies to maximise communication and enable individuals to make the most of their skills and abilities, for example, by offering use of pictures and scales. I was required to develop my skills and knowledge in order to enhance communication with individuals, as I needed to be able to make links in words, use third party approaches, listen effectively and so on. It was important for me to create a non-threatening and empowering environment, which would enhance confidence and enable the participant to feel at ease. This could be achieved through being empathic, non-judgemental and not pressuring the person, but giving them time and space to process information and reply; I needed to use broader open-ended questions; it was important for me not to be patronising or to belittle the person and be critical, but to accept their emotional reality. It was crucial that I respected the person's rights to give and withhold the information they chose to. I needed to be conscious of my relationships with individuals and attempt to equalise these as far as possible, by being friendly and building a rapport, working with participants in equal partnership to establish the best methods, avoiding jargon and so. I was also required to involve individuals in the research process, by allowing them to set the interview agenda as much as possible and facilitating opportunities for choice and involvement in decision-making with regard to the methods employed. I needed to be aware of my own beliefs and prejudices, which might hinder or bias the research process.

However, in any qualitative study, it is important to consider and be aware of the beliefs, values, motivations and interests of the researcher because these will influence the research process. My particular standpoint and beliefs impacted on the research process to a lesser or greater extent and at different stages. For example, the area of research selected is dependent on the beliefs and motivations of the researcher, as is the methodology employed and the collection, analysis and interpretation of data. The process of examining ones' own impact on a research study is referred to as 'reflexivity.' My interest in the area stems from personal and professional experience in the area of mental health and from academic qualifications in psychology. My past involvement with pro-user organisations such as MIND probably influenced selection of this particular research area. The methods employed, for example, the pictures and scales and the types of questions asked were based on my own reading, research and experiences and it is inevitable that they impacted on the data collected. Other data collection techniques may have generated more or less data.

My personal attitude and beliefs most probably influenced the process of data collection, as I responded and adapted to the needs, comments and reactions of individuals during interviews and when videoing in a particular manner. For example with regard to the follow up questions asked in interviews; placement of video microphones etc; another person may have reacted and responded in a different way. In addition, my belief, based on my own experience of interacting with people with dementia and research, was that communication with people with dementia is possible and one can attach meaning to what is said. Since I also had the benefit of prior experience of interacting with people with dementia, as well as knowledge of the techniques discussed earlier, it is possible that I was in a strong position to successfully obtain their perspectives. This may not have been as strong, had I conversely believed that communication was not possible and that what is said is nonsensical or invalid. In addition, I was willing to be flexible and adapt methods used according to individual preferences and needs. These issues relate to the professional/organisational level of empowerment. The attitudes and practices of professionals working with people with dementia can impact significantly on the level of empowerment achieved, as even if people with dementia possess the skills and abilities to be empowered at an individual level, this may not be possible or it may be diminished if factors at the other levels hinder empowerment. However, it could be suggested there was a risk that my beliefs and values not only facilitated the process of communication, but distorted the data and results obtained, for example, there was perhaps some danger of me finding meanings in accounts of people with dementia which were not there, because I wanted what was said to be meaningful. In order to address any potential bias, a number of measures were taken. These included endeavouring to take in and record all the available interview, observational and document information, rather than being selective and only seeing and documenting what I wanted to; trying to remain open minded throughout the research process and open to any unexpected results; and not imposing interpretations on findings.

My positive outlook may have influenced data collection in other ways. When I first began collecting data, I had a tendency to focus on the positive, rather than the negative aspects of care and this may have impacted on, for example, the observational notes, as these were based on my own perceptions and thoughts of the care provided. However as the study progressed and I interviewed people with dementia and listened to how they felt and spent

more time in homes, my attitude changed somewhat and I found myself becoming more critical of the care provided in the residential homes. As mentioned earlier, checks were also carried out with a second researcher, enabling a more accurate and objective account of events to be assembled.

With regard to the analysis and interpretation of the data, I may have again influenced the process, for example, in the way that I dealt with unexpected data. In addition, as mentioned, I believed that there is meaning behind what is said by a person with dementia. Even if sentence(s) appeared nonsensical or incoherent at first, I was willing to look for meanings and think about what each person was trying to say, by taking account of the context, verbal and non-verbal cues. If I had held disempowering and negative beliefs on the outset, I may not have been willing to make that extra effort to look for meanings, simply dismissing what was said. However there was again an issue of possible bias and distortion of results through over-interpretation and identification of meanings which were not there. As mentioned various precautions were taken, which included remaining open minded and being careful not to impose meanings and interpretations on what was said.

In addition, the interpretations presented are based on the data collected, but also influenced by my reading, my experiences and my research. Another person with different thoughts, interests and knowledge may have interpreted the data in a different way. In order to reduce individual bias, regular liaison and discussion took place with other members of the research team who were able to offer alternative or additional explanations, interpretations and perspectives.

(4.9) Ethical issues

Throughout the research process, there were a number of ethical issues to consider, as may be expected given that the study includes people with dementia who perhaps are not always able to give informed consent for their own participation. There were also a number of ethical considerations to take into account with regard to the methods adopted which in addition to the more traditional methods, such as interviewing and carrying out observations, included video and audio taping of individuals.

Initially, the project had to pass through the Community Fund Ethics Committee and ethical clearance was also sought from a joint Middlesex University/ Jewish Care ethics committee. This was granted after an ethics protocol, providing clear guidelines for residents, members, next of kin, carers, the research team and key organisations as to how the ethical issues involved in the research project would be addressed and monitored was devised and presented to the panel – see appendix IV. This protocol included the declared ethical issues surrounding the research, the procedures put in place to ensure ethical compliance, the setting of standards and a programme of surveillance, that is to say, means of monitoring the standards throughout the implementation of the project.

Key components of this were to share information and consult everyone involved with the project throughout the research process. It was anticipated this would be empowering for individuals at the first two stages of the service user power level, allowing some control and influence over the research process. Before selection and consent gathering processes began, information about the project was sent internally to all Jewish Care staff which included details about the sampling techniques and research methods to be employed, as well as ethical issues and issues of confidentiality. Staff included in the larger project, though not in this study, were randomly selected for participation in the study and meetings were arranged and visits made to individual homes and centres to discuss the project further and to answer any questions. Furthermore, two Jewish Care representatives were elected and appointed to a Joint Middlesex University/Jewish Care Research Project Committee. One of these represented Jewish care staff and the other service users, i.e. people with dementia and their relatives, thereby extending involvement to the third stage of the service-user power level, which relates to inviting and working with individuals to/in working groups or meetings. The Committee's task was to organise, develop, apply, execute, oversee and monitor the day-to-day operations of the research project. The same members of the committee, including the two representatives, were involved in the analysis and interpretation of the research data, thus every opportunity was offered and used which allowed for the full involvement and participation of all. It is questionable how empowering including just one service user and one staff representative was; there is an obvious issue of representativeness, i.e. how feasible is it for one person to represent the interests of all service users or staff. However, these particular individuals liaised fully with service users and staff within the different day centres and homes and were able to

present a collective view or opinion to the project committee. Updates and newsletters about the project were also distributed at regular intervals. Involving staff and service users in the research process was very valuable. Their ideas and perspectives were important to the development of the study and additionally, involvement may have been empowering for them, since they were now not only 'subjects' or bystanders in the study, but had an opportunity to play an active role in and influence the research process.

Access to sites was negotiated with individual heads of homes and day centre managers and the best time to go in established, after consultation with people with dementia, heads of homes, staff and relatives. Also, before any settings were accessed, individual homes and centres were visited and information about the project provided to residents, members and staff and any questions answered. Much effort was expended to involve service users and staff to ensure they had adequate information about the project and understood the ethical issues involved.

Apart from distributing adequate information to and liaising with people with dementia and their relatives to decide the most appropriate time to go into the setting to carry-out filming and interviews, well-being of the person with dementia was monitored throughout the videoing and interviewing process. If any signs of anxiety or stress were observed then interviews were postponed or terminated and similarly, if microphones were an irritant then they were removed. This was important because it was not always possible to obtain consent from the person with dementia. If the ability to give informed consent was uncertain, monitoring wellbeing and non-verbal responses was important to determine whether or not people with dementia were happy to take part in the study. The needs and wishes of people with dementia were paramount and if they indicated either verbally or non-verbally that they no longer wanted to be involved, their participation was withdrawn.

Additionally, participants' rights to privacy and confidentiality were to be respected at all times. Cameras were placed only in communal areas and people with dementia, their relatives and staff were made aware that they were there and that they had the right to switch off the camera if they felt that filming was inappropriate. Individuals were empowered in the sense they were able to make their own choices and decisions about videorecording and the periods when filming took place. If those not selected and

consenting to participate in the project were caught on the camera during the fieldwork, the equipment included a facility for pixilating the faces of those people. All documents, such as consent forms, file information, interview and video data were kept under lock and key. Only members of the research team had access to data and after fieldwork and analysis all data were destroyed. The anonymity of all participants was preserved at all times, as there was no mention of individual names or settings in any reports and publications and each person and setting was allocated a code, which was used throughout the research process, such as when labelling videotapes, on interview transcripts and in any publications. It was agreed that the only time that confidentiality may be broken would be under circumstances of abuse, which would be handed to Jewish Care management to deal with in accordance with their procedures. Additionally, cultural sensitivity was exercised throughout the research process, as research staff had training in the Jewish calendar and culture and there was also liaison with heads of homes, day centre managers, people with dementia and next of kin regarding timing of filming and other data gathering procedures.

(4.9.1) Obtaining consent

When obtaining consent for participation in the study, the aim was to receive informed consent from both people with dementia and their next of kin. Relatives were to be asked for consent for their own participation in the study and both people with dementia and their relatives to be approached for consent to involve the person with dementia. It could be argued that approaching relatives to include people with dementia in the study is unethical, however as is discussed, relatives' consent was simply an extra safeguard. Every attempt was made to obtain verbal or non-verbal consent from the person with dementia and individual wellbeing was monitored on an ongoing basis. The decision as to whether next of kin or the person with dementia was contacted first, was made after liaison with heads of homes and day centre managers. All individuals were provided with information about the project and asked to sign a consent form (see appendix IV, for examples of the information sheets and consent forms used). For next of kin this usually involved sending out letters and contacting them by phone and visiting them if they requested it to explain matters further and people with dementia were visited at the residential and nursing homes and at day centres. From the residential and nursing homes, consents were obtained to include 17

people with dementia and 18 next of kin and from day care centres, 10 consents were received both from members and their next of kin.

(4.9.2) Relatives' concerns about participation

Those people who were opposed to their relative taking part, were the first to reply, often in the form of a letter. A number of relatives had questions and/or concerns about the project, which they wanted answered or addressed before they gave their consent. For example, there were concerns about the use of probes, electrical equipment or medication. It was explained that the study would be purely psychosocial. The next of kin or guardian also often wanted to know how intrusive the study might be, whether it would upset their relative in any way and they wanted to know the types of questions which would be asked. Relatives were assured that there would be minimum intrusion on the lives of individuals with dementia and questions would be of a non-threatening nature. On a few occasions samples of the interview questions was sent out to the next of kin or guardian.

There was some concern expressed about the confidentiality of information given and about the publication of materials and reports. Relatives were assured that the anonymity of their relative and themselves would be preserved and that all information given would remain confidential; names of people or settings would not be used in any write-ups or reports. Many relatives were sceptical about the feasibility of interviewing people with dementia, claiming that their relative would not be much use, as they could not understand or say anything much. These comments were not altogether surprising, since it has been a commonly held belief that people with dementia are not able to offer their views. It was explained that a variety of methods would be used to elicit information from the person with dementia, which would include visual aids and also a video camera, to pick up any non-verbal responses. It was also mentioned that the research team were skilled and experienced in communicating with people with dementia.

(4.9.3) Obtaining consent from people with dementia

The issue of whether it is possible to obtain informed consent from people with dementia was a difficult one. However, it has been argued that a diagnosis of dementia does not

necessarily imply that an individual is incapable of consenting and obtaining consent, if possible, is central to the principle of autonomy (Downs, 1997). Some authors have suggested that the wishes of the person with dementia can be recognised through non-verbal communication, where as others have suggested the need for power of attorney (Downs, 1997). In this study, there were no assumptions made about the ability or inability of a person with dementia to consent, as all individuals were approached and offered information about the project and asked for their consent. The process aimed to be empowering for individuals with dementia at a service-user power level, by giving them the opportunity to make their own decisions about whether or not they wished to participate in the study.

However the process of obtaining consent was not without its difficulties. For instance, when initially visited, residents or members sometimes started talking at a tangent about other unrelated issues, perhaps because they felt much more comfortable talking about topics such as childhood experiences and family, so it was necessary to keep bringing the individual back to the topic being discussed. This was difficult because I sometimes felt I may be pressurising the person to listen to something they were not very interested in. Time spent obtaining consent from the person usually involved discussion of other topics and issues other than the research project; individuals with dementia were often very pleased to have a visitor and may have seen it as an opportunity to chat to someone on a social basis. For a few of the individuals it appeared that the time arranged to visit them was not appropriate, as some earlier incident had upset them and in these instances it was necessary to arrange to come back on another day. On reflection it may have been useful to phone just before coming to check that the person was up to seeing visitors at that time. It was clear that the participation of people with dementia would depend very much on how they were feeling on the day of the interview or filming. The research team would have to be flexible and cater to the needs of the person with dementia, rather than them fitting in with our schedule. Some people with dementia questioned how useful their participation in the project may be and comments included: *'What use could I be?'* (Ira) There was a fear of failing our expectations and disappointing us. These type of comments reflect low levels of confidence which may have impacted on empowerment at an individual level, by resulting in hesitancy to articulate views. Other people however, were very pleased to be selected to take part in the study, e.g. *"Well, it makes me feel important."* (Jessica)

Although it was often possible to obtain verbal consents, written consent from most people with dementia was unobtainable within residential homes because the dementia was too advanced. Within day care settings, written consent was obtainable from some members, but it was sometimes difficult to know whether the person with dementia fully understood what they were being told about the project. Because of problems with short-term memory, individuals had often forgotten what they had heard a few minutes ago and when it came to giving consent it was sometimes questionable whether it could be called informed consent. For me this was a difficult issue, as the person with dementia may have consented to participate in the study, but it was not always clear whether they were aware of what they had agreed to or if they had fully understood the implications of being part of the project. There was a dilemma about whether to include the person in the project or not. Additionally, although an individual with dementia may have given their consent on one day, they may have forgotten about it by the next day. This is where obtaining consent from relatives was important, however, there is an ethical dilemma here, as it could be argued that a relative may have consented for the person with dementia to participate in the study, but that individual may not themselves have given their consent had they been fully aware of issues involved, which would not be very empowering, in fact positively disempowering. To address these issues, the following measures were employed: to resolve the problem of people with dementia forgetting they had consented to take part, they were provided with information and consulted about their participation in the project on an on-going basis. If they changed their minds about being involved at any time, their participation was withdrawn. To address the dilemma of including a person when there was some uncertainty about their ability to give informed consent, their well-being was monitored throughout the research process. If the person with dementia indicated either verbally or non-verbally that they no longer wished to participate half way through the research project, or there were any signs of distress, equipment, such as microphones were removed and interviews were postponed or terminated.

PART TWO

The Findings, Interpretations and Discussion

5 THE RESULTS: A BRIEF OVERVIEW

This chapter provides an overview of the results which are presented and discussed in full in chapters six to ten. It examines briefly the findings in relation to the different levels of empowerment, exploring the data which relate to obtaining accurate information from people with dementia and those which consider whether relatives can represent the views of individuals with dementia. It summarises perceptions of people with dementia and their relatives about care services and their experiences of dementia. The different types of data gathered and how these relate to each other receive consideration in brief.

(5.1) Empowerment and the individual

(5.1.1) Eliciting accurate views from people with dementia

The analysis of interview data indicates that it is possible to elicit dependable views and feelings from people of a range of severity of dementia, that is from people in the early, through to the more advanced stages of dementia. These results demonstrate potential to begin the process of empowering people with dementia, at an individual level, by obtaining their views. Responses about services, experiences of dementia or other unrelated topics were obtained from all participants interviewed - verbal responses from 22 out of the 27 individuals with dementia and non-verbal responses from all 27 participants. Views about services were obtained from 19 out of the 27 individuals, 9 of whom were people in day care settings, most of whom had early onset dementia, and from 10 people within residential services, who tended to be in more advanced stages of dementia. As is discussed in detail in chapters six and seven, these views were supported by the video and observational data, suggesting they are accurate and challenging conventional beliefs that the perceptions of people with dementia are unreliable.

The different methods employed to obtain views are explored in depth in chapters four and ten but include interview questions for those in the early stages of dementia, and the mood scale, pictures and photographs for those with more advanced dementia. The findings demonstrate that it is effective to employ multiple methods and that an individualised and

flexible approach, using combinations of different strategies for different people is helpful. Qualitative methodology was particularly suited to the unpredictability of research in this area. Adopting a multi-method flexible approach allowed different methods to be used with different people or in differing real life contexts and this allowed for richer more contextual data. The data collection techniques and the process of research more generally aimed to empower people with dementia. It was hoped that participation in the project was beneficial for participants and would make a positive difference to their circumstances and wellbeing. All findings were fed back to Jewish Care on the understanding that they would incorporate recommendations into their practice and a number of personal benefits for participants were identified which are described more fully in chapters six to nine. These included, increased self-esteem, opportunities to articulate views and feelings and socialise and meet new people.

(5.1.2) Experiences of dementia

The results of this study contribute to the small, but growing body of literature on the subjective experience of dementia. A significant amount of information was obtained from participants and this was supplemented by the video and observational material and relatives' accounts. Data presented in chapter eight demonstrates how, with the onset and progression of dementia, individuals felt very disempowered. At an individual level, various mental and physical abilities, such as memory, communication, mobility and driving skills were affected, which impinged on self-confidence, restricted the ability to communicate and resulted in feelings of powerlessness and loss of control. These difficulties were exacerbated or eased by other people's behaviours and attitudes, supporting suggestions that levels of wellbeing and empowerment can be influenced by the person's social environment (Kitwood, 1997).

As discussed in chapter nine, the findings unearth the immense psychological, social and physical pressures endured by the relatives of people with dementia and how these impact on feelings of control and wellbeing at an individual level. Relatives experienced loss of power over their lives and the lives of their loved ones. They did not know what to expect or what would happen next and there was nothing they could do to help their relative and ease their own distress. Loss of the person with dementia and with this the loss of their

relationship resulted in feelings of devastation and pain which impacted hugely on individual wellbeing.

(5.2) Empowerment at the level of the organisation

(5.2.1) Perceptions of people with dementia about care services

The views of people with dementia about the quality of residential services are described in chapter six and the data reveal how they felt disempowered by some aspects of care, in these settings. A lack of stimulation, influence and control were identified. These perceptions were supported by observational and documentary evidence, as there was clear evidence of a dearth of stimulation, a lack of choice and independence and files notes indicated that people with dementia had little or no involvement in CPA meetings or reviews. The results suggest that dependable views are obtainable from people with dementia.

Perceptions of day care services are discussed in chapter seven and the data show that day centres and particularly special day care centres were viewed more positively because they provided a high quality of care. Care practices were generally more empowering, as levels of stimulation and opportunities for control and influence were described to be higher. The reliability of the views of people with dementia were borne out by the video and observational data.

Interactions with informal carers, such as friends and family members sometimes impinged on wellbeing, for example, family and friends sometimes distanced themselves, leaving the person with dementia feeling alone and isolated. On other occasions, for convenience or safety, they took over and did too much for the person, restricting their freedom and leading to feelings of loss of control and disempowerment at an individual level.

(5.2.2) Relatives' perceptions and issues relating to representation

The relatives' views of services and their perceptions of how the person with dementia felt are discussed in chapters six and seven and their comments were generally very positive,

reflecting the views of people with dementia in the day care phase, but differing considerably in the residential phase. The data suggest that relatives are not always aware about the feelings of people with dementia and do not always have accurate knowledge about services. The video and observational data confirmed the perspectives of people with dementia but refuted the views of the majority of relatives. The reasons for this are discussed in later chapters, but included difficulty communicating with the person with dementia or spending little time with them in the service setting. It also appeared that they were very grateful for the support received and were therefore uncritical or were in denial of adverse aspects of care, as it was too painful to think of their relative as unhappy. The findings strongly suggest that it is important to consult with the person with dementia themselves when seeking their views about services.

The findings reveal that relatives often felt disempowered within the residential homes, as they did not always receive adequate information, were not consulted about their relative's care or included in CPA reviews. They were also disempowered because they were not given the information and support they needed to sustain them in their caring role.

(5.3) Empowerment at the level of the service user

The service user power level relates to the amount of power and control individuals have, that is, the extent to which they have choice, are involved and consulted. With the onset and progression of the illness, people with dementia were disempowered, as they gradually lost influence over their lives. Their independence was lost as they became less able to walk or drive; communicate their views and feelings; and for reasons of safety and convenience were sometimes locked into their own homes or forced to move into residential accommodation. Levels of control were influenced by the behaviour of other people, for instance, practices within residential settings impacted on their ability to be self-determined. People with dementia barely had opportunities for involvement at a consumerist level, let alone at an empowerment one, as they were not even able to make choices. There were higher levels of influence and choice within day care services, but since there was limited opportunity for participation at a higher level, involvement tended to be at best of a consumerist nature.

With the onset of dementia, relatives experienced feelings of helplessness and distress, as they did not know how to or feel able to deal with and cope with the difficulties and changes they were experiencing. Appropriate support and information had the potential to enhance feelings of control and power, but these were lacking and difficulties experienced with accessing help and support actually served to increase feelings of powerlessness.

(5.4) The level of the society

Experiences of dementia and services resulted in reduced quality of life and opportunities for both people with dementia and their carers. They found themselves denied the lifestyle they had before and to a great extent excluded from many aspects of life enjoyed by others in society.

(5.5) Coping

The data, which are discussed in later chapters, demonstrate that people with dementia responded to and coped with their experiences in different ways. Individuals sometimes coped by denying there were any problems, withdrawing into themselves or becoming aggressive, angry or obsessive. Other people accepted the situation, used humour to get them through the day or found it helpful to keep active and involved. Relatives developed their own coping strategies, which enabled them to gain some control over their feelings and circumstances. These included acceptance of the situation and getting on with things, seeking help and support, avoidance and denial of any problems.

6 VIEWS ABOUT RESIDENTIAL AND NURSING CARE

As outlined in chapter four, 28 people with dementia and their next of kin were randomly selected from eleven of the Jewish Care homes. These are situated in North West and North East London, Redbridge, Brighton, Hemel Hempstead and Southend. From these, consents were received to include 17 people with dementia and 18 next of kin. Residents consenting to participate in the study were in later stages of dementia compared to those in day care; they all had a diagnosis of dementia; two were male and 15 were female; and they resided in five of the different residential and nursing homes. Twelve next of kin were sons and daughters, three were spouses, two cousins and one a friend.

This chapter is divided into two parts. The first explores the views of people with dementia about residential and nursing care in relation to the different levels of empowerment and the second deals with the perceptions of their relatives. A variety of methods were used to elicit views. Tape-recorded interviews were conducted with the majority of participants and in addition, some people with dementia made use of the pictures and the mood scale which helped them to answer the questions. In using the different research techniques, every effort was made to adopt the principles of empowerment as much as possible, for example, time was given to building relationships with participants and individuals were encouraged to take the lead in interviews and make their own choices and decisions about the methods employed – see chapter 4. Video and observational data provided supplementary information and were cross-referenced with interview data in order to support the rigour of interpretation.

Results show that eliciting reliable and clear views from people with dementia is possible and it is therefore feasible for people with dementia to be empowered at the individual level. An aim of the study was for involvement to result in personal development or at least be personally beneficial to participants, and results suggest this goal may have been achieved to an extent. The interview narratives suggest that for some of the informants,

involvement in the research process helped to meet socialisation needs. They suggest an increase in self-esteem and individuals feeling empowered in the sense they were able to articulate their views and have a say. Comments included:

“Thank you very, very much. It been a pleasure talking to you. I want you to know, if ever I can be of any help – don’t hesitate to ask me. (Adah)

“It makes me feel important.”(Jessica)

“You’ve helped me so much – the way you put questions. They’re not heavy or too heavy ... it’s been much easier for me...It’s much better and I can not hesitate so much...thank you dear, you’ve helped me a lot by the freedom of it.” (Stephanie)

While it is not possible to be categorical about the effects, it would appear that the interaction involved in the research process and the manner in which it took place are consistent with the ethos of empowerment. At the least they demonstrate the merits of involving users in things that affect them.

Although the results show that it is feasible to empower people with dementia at an individual level, analysis of data revealed that people with dementia did not always feel empowered in the residential and nursing homes. Unfortunately and as is detailed in this chapter, external factors at the level of the organisation, such as the environment and other people’s attitudes and practices, hindered levels of empowerment. Opportunities to influence and control aspects of daily living and some of the other components of quality of care, such as levels of stimulation and communication were described by people with dementia to be inadequate. The majority of these views were supported by the video and observational data, suggesting them to be accurate indicators of the care provided. Relatives’ views tended to be more positive than those of people with dementia, but were unsupported by the video and observational data, suggesting them to be undependable in many instances. The reasons for and implications of these findings are explored in this chapter.

(6.1) Residents' experiences of care received

As mentioned, many clear views were elicited from people with dementia about the services they received, suggesting that they do possess the skills and abilities to be empowered at the individual level. Responses of some kind were obtained from everyone, although views on services were elicited from only 10 out of the 17 residents. These views demonstrated areas of satisfaction and dissatisfaction with the care received (see appendix V for a summary). Experiences of people with dementia are discussed below, in relation to the different levels of empowerment:

(6.1.1) Disempowering practices at the level of the organisation

The comments of people with dementia suggest they were disempowered by factors at the professional/organisation level. Some of the systems and practices within the homes meant that they did not have access to the same quality of life and opportunities taken for granted by many others. As is discussed below, aspects of quality of care provided by the organisation were inadequate. Five residents openly indicated that they were unhappy to be in the home and there were a number of reasons for this, which included feeling bored, uninvolved and that they had little control over their lives. Katherine was frequently observed to be upset in the home and she described her intense dislike of it:

*"I hate it – this bloody place – suppose I've got to spend the rest of my life here."
(Katherine)*

Katherine talked about missing her past life immensely. She spent much of her time in the home sitting alone doing very little or looking at the newspaper and talked of feeling trapped, as she could not go out unless her family came to take her out, but they did not visit very often. One feature of all of the homes, which may have felt very disempowering for Katherine and the other residents, was that they were locked to prevent people wandering out and getting lost, so residents were not able to come and go freely. From the organisation's point of view, there may have been a dilemma about the need to maintain safety and empower individuals by allowing them to make their own choices and decisions about where they wanted to go and be. Perhaps a solution would have been to have

someone available to accompany individuals on outings, that is, if staff numbers allowed this. Alternatively, perhaps a space or garden area could be created outside, where residents could wander at their leisure, as it would be important to find ways to promote both safety and autonomy.

Another resident, Ruth, repeatedly indicated the unhappy face on the mood scale, when asked what it was like for her in the home and in reply to subsequent questions about the care she received. Nobody listened to Ruth or paid her and her needs much attention, and she was left sitting all day. This individual was in a more disadvantaged position, because her dementia was further advanced and she was immobile. She may have felt particularly powerless, as she had far less choice about where she sat and with whom, because she was unable to move around freely or even insist that she be moved. She spent much of the day shouting for the toilet, not necessarily because she wanted to go to the toilet, but perhaps because the occasions she was taken were the only times that she received any attention. A combination of Ruth's disabilities and practices within the organisation resulted in Ruth having very little influence over her life and her quality of life was low.

Only two residents described feeling relatively happy. Their comments suggest that they felt more empowered, as their wellbeing and quality of life were enhanced as a result of being in the home. Both of these individuals had felt isolated at home, because their spouses had died some time ago and they rarely saw friends or family members and were therefore pleased to be surrounded by other people. It was also sometimes somewhat comforting to be a home, as it provided a safe environment and individuals did not have to cope with numerous responsibilities as they had had to at home. Interestingly however, these two residents were also among those who indicated that they would find it difficult to complain, an issue which is discussed later in the chapter.

Sitting doing nothing

Comments suggest that the quality of care provided fell far short of what residents would have liked and expected. Feelings of boredom and uninvolved were major issues for residents. Nine individuals indicated a lack of stimulation, either with regard to activity or levels of contact with other people. They often felt that there was little to do and much of

their time was spent sitting doing nothing, as although activity occasionally took place, there was not enough to provide sufficient stimulation. Additionally residents were not often given the opportunity to get involved in tasks around the home as most things were done for them and there was no sense of feeling part of what was happening around them or to them. Joanna, who had been living in the home for about three years, had previously had a very active life and she described how frustrated she felt now:

“Life is terrible for me, because I was always so active and sporty, you know, and now I can’t do much at all. This is no life...there are no activities at all. I’ll be downstairs and sleep a lot and read my papers and then I go up and watch television and read my papers and so on and then I go downstairs again.”(Joanna)

As she described, she spent most of her week in the lounge downstairs, sleeping or reading her newspaper, or upstairs watching the television. There was very little opportunity for her to go out anywhere and she did not interact with people very often. Her comments are typical of those expressed by many other residents, for example, Adah, a former cabaret singer who had been used to much entertainment, going out and meeting and talking to people, commented on the lack of outings and activity in the home:

“We don’t go anywhere, where do we go?...If we did go out very often that would make me very happy.” (Adah)

Adah also spent all day sitting in the lounge doing very little, other than intermittently interacting with the person sitting next to her or taking part in an occasional activity. Likewise, Jessica, a very sociable, gregarious person who liked to be involved and to be busy, spent much of her time just sitting in the communal lounge and she described feeling very bored and sometimes disappointed in the home:

“I feel, very, very, waiting to do something. I need something, you see...You know, you think you’ll do so and so – when you go to do that so and so, it doesn’t – it’s harder to do ...sometimes I’m disappointed, then it wears off.” (Jessica)

Jessica was not sure what she needed, but knew something was missing and her comments suggest that she tried, but failed and that maybe with help she could be occupied. They also indicate that she gives up after a while, which could be her way of coping with the disappointment and upset experienced. It was a drastic change for people like Esther:

"It's the sitting, I'm not used to it." (Esther)

Stephanie exemplifies the effect the lack of activity had on residents:

"This place is driving me mad." (Stephanie)

In support of these comments and perceptions, video and observational data revealed there to be minimal activity within the homes. This took place at most three times a week, if that, when perhaps a music therapist would visit or there would be an exercise class. For most of the week, residents were left sitting in the communal lounge with very little to do, other than perhaps watch the television. In line with their comments there were no outings, unless families of individuals chose to take the person out, which was not very often. Residents appeared to be bored, often slumped in their chairs, falling asleep or wandering restlessly trying to occupy themselves.

Limited interaction with people

Communication and good relationships between professionals and service users are central to empowering practice, however the comments of people with dementia suggest there were difficulties in these areas. Although residents appeared to like staff, they indicated they had limited contact with them; interaction tended to be minimal and predominately task orientated. Jessica described staff as very busy with their own work and not having sufficient time or not wanting to spend long conversing with her; she felt worried that she was taking up too much of their time:

*"They're (staff) nice to me, quite friendly you know, that sort of thing, if there's anything to say, but they're always so busy, doing things for themselves really."
(Jessica)*

She refers to staff as ‘them’ and by implication other residents and herself as ‘us,’ which suggests a barrier or distinction between staff and residents in the home. Her comment that staff were ‘doing things for themselves,’ suggests that they were not doing things for her or other residents. Joanna said that she did not always feel listened to by staff:

“The staff are alright, but if I ask something, sometimes I get it, but sometimes I don’t – they don’t listen much.” (Joanna)

These remarks about staff not having much time to listen or talk and references to a possible divide between staff and residents have implications for empowerment. As discussed in previous chapters, equal, trusting relationships are crucial if empowerment is to be implemented effectively, as is a willingness to communicate and consult with service users, but comments of people with dementia suggest these elements were lacking. At an organisational level, it appeared that there was little time for or value placed on communication and building relationships with individuals.

Nobody described liking any particular members of staff, or having better relationships with some than others. It appeared that they did not see staff for long enough to develop a bond with any of them, as they seemed to be too busy doing other more important things to stop and talk for any length of time. The narratives of people with dementia were again supported by the video and observational data, which revealed minimal interaction between staff and residents. Any communication was brief and predominantly task orientated; there was very little social contact; and as indicated by participants with dementia, staff appeared to be too busy doing other things, to stop and talk to them.

Interaction with other people within the home was also minimal and there was little evidence of any attempt by the organisation to facilitate communication or friendships between service users, which arguably would have significantly increased quality of life. People with dementia did not really mention other residents as particular friends, but fellow residents were usually considered to be merely acquaintances, with whom interaction was sometimes enjoyed:

“Yes, I like it, I’m not on my own, you know. I’ve got all these people around and I sit next to people, we talk to people and so on.” (Adah)

Some residents wanted minimal contact with others, perceiving them to be frightening, odd or strange, in the way that they spoke or behaved, for example Stephanie, who was in earlier stages of dementia than the majority of people in her unit, described the others as “funny”:

“My mother wouldn’t like me to be in a place like this with these people...funny people in here.” (Stephanie)

She refers to her mother, indicating that she is in a different place in time – somewhere in the past, however her feelings about her present situation and the people she is living with are very clear. Another resident, Abigail, also described other residents as strange in the way they just sat or slept in their chairs without talking to one another at all; she thought them to be rather unfriendly and drew attention to this:

“People are just sitting there like that. Look! They’re not friendly. They don’t talk to one another.” (Abigail)

One possible explanation for residents feeling this way may be that others were in more advanced stages of dementia and therefore they may have appeared strange in the way they behaved to someone with early onset dementia. There was nobody in similar stages of dementia that they felt able to relate to and communicate with. This may also reflect a lack of communal activity, which may have led to more interaction and establishment of relationships with others who individuals felt better able to relate to.

In addition, residents did not always see visitors, such as friends or relatives often or as frequently as they would like. They explained that homes were some distance away from where they lived; they were busy at work and with their families at home; or that they simply could not be bothered. The nature of the homes was such that once individuals had moved into one, contact with the outside world was hugely reduced; there was little

opportunity for residents to go out and few people came in and only for limited periods of time. When asked whether she had many visitors, Jessica replied:

“Not many – no – I think it’s out of their way that’s why. It’s a wee bit...something like that. No they don’t visit me. I give them a call or something like that.”
(Jessica)

Other comments included:

“It’s very awkward for them, because they have to go to work and they can’t always come, but they have been occasionally when they’ve been able to.” (Adah)

Jessica and Adah seemed to be making excuses for or defending their relatives by trying to explain why they were not able to visit very often. Alternatively perhaps they were protecting themselves and their own feelings of rejection by trying to rationalise their relatives’ infrequent visits. Ruth, on the other hand, was openly upset and angry that her son did not visit her very often:

“No he can’t be bothered I don’t think.” (Ruth)

Ruth, Adah and Jessica were all in earlier stages of dementia and although they were not able to live in their own homes safely anymore, were very clear about their feelings.

The observational and video data again supported perceptions of people with dementia, as it showed that interaction with relatives, friends and other residents was limited. On the whole, relatives and friends were not observed to visit very frequently and were not present for long periods of time. An hour or two with their relative a week may have seemed like very little time to residents who were sitting and waiting for someone to come or someone to talk to all week. Also supporting the perceptions of people with dementia, on the whole, interaction with other residents was observed to be minimal and on several occasions residents had noticeably been ‘misplaced,’ in that they had been put in an environment, where their dementia was significantly more or less advanced than other people around them. One issue on which the video and interview data conflicted however

relates to individuals having particular friends. There were a couple of individuals who were observed to have special friends, who they spent much of their day with, however none of the participants indicated having particular friends.

Lack of Choice and Independence

Empowerment at the level of the organisation requires that professionals work with individuals to maximise their potential and enable them to have as much control over their lives as possible. However, as may be expected given that there was a lack of communication and consultation, the levels of influence and control were described to be low. There was little indication of attempts to involve residents in their care and enable them to make their own choices. Six individuals spoke of a lack of choice or independence in the homes, in relation to meals, day to day routine and personal care, for example, there was not always much choice with regard to the food available and the way that it was cooked. Joanna commented:

“Chicken you get, but the way they do it, I’m not very keen.” (Joanna)

Perhaps Joanna was drawing on her own ways of cooking and her particular likes and dislikes, which remained although her memory had deteriorated.

Adah made a decision that despite the lack of choice she had to eat:

*“Much choice? Not a great deal of choice, but whatever is given to me, I eat it.”
(Adah)*

When asked about the type of things that she enjoyed doing in the home, another resident, Abigail, formerly a very independent person who had owned and run her own two businesses, replied:

“Anything really, I’ve got no choice.” (Abigail)

As well as having dementia, Abigail was also now immobile, so had very little autonomy in the home and may have felt very powerless.

Again, supporting the views of people with dementia, video and observational data revealed low levels of influence and control for residents in the homes. On a day to day basis, there was little choice or opportunity for involvement offered in relation to food, activities, routine and so on and independence was not promoted. Individuals were observed to do what they were told, they generally followed the regime of the home and conformed to what was expected of them.

Reluctance to complain

In an empowering environment, service users should feel confident to express any concerns or reservations in relation to the care they are receiving, however five of the 17 residents indicated that they would be reluctant to complain. For example, Adah spoke of feeling frightened of the consequences of this and how she may be treated as a result and for this reason had decided that she would rather not make any complaints:

“No, I’d rather ignore it because I don’t want to start, because when you start a business, you’ve got no idea about how it’s going to finish – how it’s going to affect you – you never know. You don’t know what other people are like...” (Adah)

Remarks such as this suggest power imbalances or unequal relationships between staff and residents, which may stem from disempowering practices and cultures in the homes. These may be expected in such establishments, as the structures are such that residents are very dependent on staff for every aspect of their lives (Schmidt, 1981, 1982). Staff are in a position where they have the power to reward or punish service users, no matter what they do and residents are in a vulnerable position with very little power (Muir-Cochrane, 2000). Adah may have recognised this and been reluctant to complain for this reason; she did not want to be perceived as a troublemaker by staff and risk punishment. This has significance for other levels of empowerment, as a reluctance to complain may result in reduced individual wellbeing and quality of life, since needs and wants are overlooked.

The physical environment

The environment of the home was sometimes disempowering for residents, impacting on self-confidence and levels of control. Being in the home with dementia was at times a frightening and confusing experience, particularly at the beginning. Homes were often large and there were numerous people living in them and others such as staff and visitors constantly coming and going, frequently many more people than individuals with dementia were used to. Additionally, there were new routines to adapt to, new people to become acquainted with, the environment was unfamiliar and everything was in a different place to where it had been at home. There were a huge number of things to learn and remember, which would be overwhelming for most people, but particularly for somebody with dementia who finds it more difficult to remember, learn new things and adapt to new environments and routines. For example, Stephanie described how confused and bewildered she felt:

“I never know where I am. This is a big place – more people than I thought. Where do we eat? I haven’t seen my mother. No one brought my mother up. My head’s going mad.” (Stephanie)

Stephanie again refers to her mother, indicating that at that moment her sense of time is different to that of others around her, however this does not necessarily mean that her comments are invalid and should be disregarded. She is commenting on the home she is in, and her feelings about this and her present situation are very clearly expressed. A mother or parent may symbolise love and protection and perhaps Stephanie felt in need of her mother at that time as she felt abandoned, vulnerable and frightened in the home.

(6.1.2) Higher levels of empowerment in relation to some aspects of care

Participants with dementia indicated some aspects of quality of care to be better. As mentioned earlier, two residents were more positive about the environment provided by care homes because they had been living alone prior to relocating; sometimes individuals had felt very lonely and so appreciated the company of other people in the home. It had not always been easy for them to get out and about by themselves or to meet or visit other

people, because of mobility or health problems and they had become isolated. Adah, who had lived all alone before the move and who rarely saw her family, as they were busy at work and with their own lives, described enjoying the company of other people:

“I was happy I was brought here, because I’m not alone here and it’s a pleasure not to be alone.” (Adah)

Another resident, Joanna, described her initial reluctance to move into the home, but talked about feeling more positive about the move now.

“In the first time it wasn’t alright. But I didn’t feel well. Now I feel better than sometimes when I was in the house.” (Joanna)

Joanna had found it progressively difficult to cope with living alone and to care for herself and her house. She also described feeling increasingly vulnerable before moving into the home and of falling several times on the road. Therefore, although the care home environment was disempowering for some, Adah’s and Joanna’s comments suggest it may have been more empowering for others, enhancing rather than reducing confidence and quality of life.

Other aspects of the physical environment were thought to be adequate, for example, the decoration and the chairs and other furnishings were generally described to be comfortable,

“I think it’s very easy isn’t it? Am I right? There’s not a lot of decoration. It’s just made comfortable.” (Jessica)

“I think it’s very, very nice – nothing wrong with it and the colours are very nice – lovely.” (Adah)

It was sometimes thought to be a bit noisy, but this did not present a problem to anybody. It is possible that people may have become accustomed to the noise or just not hear it.

“It’s not noisy often – occasionally it might be and if it’s occasional, that doesn’t bother me.” (Adah)

Residents were satisfied with the levels of privacy. Although all individuals interviewed did not have access to high levels of privacy during the day, as the bedrooms of residents were often locked, this was not indicated as problematic by anyone. People with dementia were usually pleased to be around other people, as sometimes they had been lonely and isolated at home. Adah described how pleasant it was to have other people around:

“I’m happy to be with other people. I wouldn’t like to be terribly alone, because I’ve often been alone. I’ve got no brothers, no sisters, I was always left alone, but at least here I’m not alone.” (Adah)

Additionally, nobody indicated a lack of privacy with regard to personal care, such as bathing and toileting.

Similarly, no dissatisfaction was expressed in relation to cultural or religious issues, as residents generally felt that their cultural needs and values were respected. The only problem occasionally voiced was that staff were rarely Jewish and in many instances Black and some Jewish residents were not entirely happy about being looked after by Black carers, and were occasionally abusive or antagonistic towards them. For example one resident who lived in a home where there was a Black manager, talked about the ‘servants’ running the place and how inappropriate that was.

The observational and video data again supported perceptions of people with dementia. The homes were aesthetically pleasing and cultural needs were observed to met in terms of food; each home had a synagogue or place for prayer; there were culturally appropriate pictures and inscriptions on the walls and so on. In addition, as described by residents, in a couple of the homes there were black managers and a few incidents were observed where residents were verbally racially abusive towards carers; behaviors which may have impacted on staff work practices and their behaviours and attitudes towards residents. They without doubt would have hindered the establishment of trusting, equal relationships between residents and staff which are so important for empowerment.

(6.1.3) Impact on other levels of empowerment

The different levels of empowerment are closely interrelated, and it is likely that practices within the homes impacted on other dimensions of the empowerment model. At an individual level, feelings of powerlessness and unimportance may have been common among residents. The data revealed that many of the people interviewed were formerly very independent and largely self-sufficient people, having lived alone and fended for themselves over several years and they were now in an environment, where there was little room for autonomy. The lack of choice and stimulation sometimes resulted in feelings of low self-esteem, for example, Jessica, who had been a very independent and active person and had worked up until a late age, commented:

“I need something you see. I’m not included in a lot of things here because I suppose I’m not fresh enough or something – I don’t know.” (Jessica)

The statement above is very meaningful. Jessica is indicating that she is not included in many things in the home and she has thought about this and has rationalised it. She feels this may be because she is inadequate in some way or perhaps too “old.” During interview, Jessica spoke of memory difficulties and of how embarrassed and incompetent she felt as a result of these; exclusion and uninvolvedness may have further accentuated these feelings and contributed to increased confusion.

In addition, with the transition from home to care, many losses were inevitably experienced, sometimes resulting in feelings of grief and depression. Residents experienced loss of their homes and sometimes felt abandoned and very alone, as they did not see relatives or friends as often as they would like. A number of residents described missing their homes and families, for example, Katherine, an 85-year-old lady who had been living in the home for two years:

“I can’t bear to talk about it...I had a lovely home, I have four sisters, but I never see them now.” (Katherine)

People with dementia sometimes had limited insight into why they were in the home, as they may not have been fully aware of previous behaviours and safety issues and all were unaware of their diagnosis. This was apparent when they were interviewed and from conversation with relatives and staff members. In some instances, family members had chosen to withhold the diagnosis, in others, individuals were not acknowledging it, perhaps because they had forgotten or were in denial of it. The lack of understanding of what was happening and why may have left individuals feeling bewildered and scared.

Also at an individual level, the abilities and skills of people with dementia may have been affected by practices within the organisation. There was little evidence of any attempts to identify, support and build on these, for example, communication was not facilitated or encouraged and walking, eating and other skills tended not to be promoted.

People with dementia may also have felt disempowered at a service-user power level and at a societal inclusion level. As described, the levels of consultation, choice and control within the homes were limited and the inadequate aspects of care described resulted in low quality of life and opportunities for people with dementia.

(6.2) Confirmability of residents' views

As discussed in previous chapters, in addition to being interviewed, each person with dementia was videotaped for a period of one week, 7am to 7pm, during which time observations were also carried out. The data obtained from these different methods were then triangulated and data were compared and scrutinised for similarities and differences. Video and observational data supported comments of people with dementia, a finding which has major consequence for empowerment of people with dementia whose views might not previously have been taken seriously. It demonstrates that what people with dementia say can be accurate and it suggests that it is feasible to empower them, at least at an individual level. As people with dementia described, video data revealed some aspects of quality of care provided to be inadequate, as there was very little stimulation provided during the day; activities, such as music therapy, took place at most three times a week and for the remaining period residents were left sitting in the lounges. Care was very task orientated, focusing on physical chores such as feeding, bathing and toileting and taking

very little account of social and emotional needs. Consistent with residents' comments, it often appeared that they were bored, because they were sitting all day, not talking to many people or engaging in many activities. They were also sometimes seen to be falling asleep, shifting around restlessly, wandering or actively seeking attention from others. This may have been through trying to engage staff or other residents in conversation, although they did not always receive the response that they may have wanted. As people with dementia indicated, partnership working and rapport between care staff and residents were not observed. Staff came across as extremely busy some of the time and were seen to almost brush residents off when they sought any prolonged interaction with them. Apart from stimulation, individuals with dementia were also sometimes in need of reassurance and comfort, because they were feeling confused or frightened, but this was rarely observed to be provided. Care staff were not always busy, but were seen to prefer to do other things, like read the paper or chat among themselves, rather than interact with residents. This is reflected in the comments of a resident quoted earlier, who said that staff were too busy doing things for "themselves" to be bothered with her. Residents were observed to then seek other means of obtaining attention, such as behave aggressively or unsociably, which did eventually achieve the desired effect. Analysis of video and observational data revealed that when there were longer periods of contact with staff or other residents, there were generally calmer behaviours. For example, one resident was frequently observed to walk around banging on the furniture and hitting other residents, but on occasions when she received more attention from staff, she appeared happier and calmer. Similarly, another resident spent a significant amount of her day wailing, while sitting in her chair in the communal lounge or in the dining area. Mostly she was ignored, but on the few occasions that staff paid her more attention, these behaviours were reduced.

The video and observational data also largely supports the residents' accounts of their interactions with other residents and visitors. On the whole, relatives and friends of many residents visited infrequently and for short periods of time. Interaction with other residents was observed to be casual or limited, and this was particularly true of those who were in more advanced stages of dementia and those who were immobile, who seemed to interact little with those around them. An example was given earlier, that is Ruth who spent much of her day sitting in her chair alone shouting for the toilet to obtain attention. Environmental factors did not always help facilitate communication as sometimes music

was too loud to be able to have a conversation and furniture was placed in such a way that interactions with others was difficult, for example, chairs tended to be set out in rows, making it difficult for residents to see the person next to them. As mentioned, the only discrepancy between views of people with dementia and the video data was that a few residents were observed to have particular friends with whom they spent a large amount of the day, sat next to at meal times and so forth, however in interviews, no residents indicated having special friends. An explanation for this may be that perhaps they had forgotten. Maybe they had no memory of their friend because of poor short-term memory, but they would have recognised an individual as a friend when they saw a familiar face. Alternatively they may not have perceived those people to be as important as they may have appeared to an observer. This discrepancy suggests that it is very important to consult with individuals themselves about their views and feelings, as what may be perceived as happening or to be true by another person may not be the reality for the individual concerned. It is impossible to be sure of what somebody is thinking or how they are feeling, without eliciting their views directly. If it was true that individuals did not have particular friends, and most were observed not to have, it suggests the need to facilitate an environment with more opportunities for social contact.

Also in line with perceptions of people with dementia, levels of choice and independence were observed to be relatively low. Residents had minimal influence and control over routine and the structure of the day; they had little say in activities that took place, times they ate, were taken to the toilet or went to their rooms, especially if they were immobile. Sometimes residents were observed to be wheeled in chairs, when they could walk, or they were instructed to sit down when they wanted to walk around. They were generally not encouraged to actively participate in tasks around the home and spent most of their day sitting in their chairs. In addition, file notes indicated that people with dementia were never included in CPA meetings or reviews. As may be expected involvement at a higher level was not observed either, as there were no resident-consultation groups within the home and residents were certainly not invited to working-group meetings with professionals or encouraged to set up their own initiatives. Practices in the homes were very institutionalised, reflecting accounts in the wider literature such as Goffman (1961), Townsend (1964) and more recently Sidenvall (1999) and Mitty (2005).

The video and observational data also supported residents' perceptions of their physical environment, as homes were observed to be well decorated, comfortable and clean. In keeping with views of people with dementia, cultural and religious needs were observed to be met, for instance, kosher food was always provided, religious festivals celebrated and physical aspects of homes were culturally appropriate, although very few Jewish staff were observed in homes. In line with comments of residents, some of the staff were black and racist behaviour was observed on occasion.

(6.3) Relatives' views about care provided

(6.3.1) Relatives' perceptions of how people with dementia feel about the care received

Empowering practices at the level of the organisation

A summary of responses is provided in appendix V. In contrast to comments of people with dementia, 16 out of the 18 next of kin thought that their relatives were happy with the quality of care provided by the organisation. Typical comments included:

"Well, I would have thought that she would see it very favourably." (Samuel, son)

*"I would say he's quite happy there and contented. He's not unhappy there at all."
(Olivia, wife)*

The majority of relatives were under the impression that people with dementia liked the staff very much,

"My impression is she likes them." (Benjamin, son)

"I think he likes the staff very much." (Sophie, wife)

"She's always given me the impression that they're very kind." (Joel, son)

These views differed to those of people with dementia, several of whom spoke of feeling unhappy with some of the practices within the homes, of wanting more interaction with staff, of not always feeling listened to by staff and of sometimes feeling frightened to complain, because they were fearful of how staff would react and so on. In addition, although people with dementia did not always like the food and spoke of a lack of choice, relatives thought that they thoroughly enjoyed their meals. From their observations, residents were provided with three meals a day, as well as tea, coffee, biscuits or cake in between. Breakfast was provided in the morning and lunch and an evening meal usually consisted of three courses, which were well presented and appeared to be appetising.

“I’ve seen all the meals and I can’t see how anybody could possibly not like it, because it’s lovely food – it’s wonderful food, very nourishing.” (Olivia, wife)

“The food is excellent.” (Rachel, daughter)

(6.3.2) Relatives’ views of quality of care

Higher levels of empowerment at the professional/organisational level

Again in contrast to views of people with dementia, on the whole, relatives’ own perceptions about the care provided by the organisation were also very positive; they were generally happy that their relative was looked after. Typical comments included:

“Excellent, excellent. I’ve got no complaints.” (Samuel, son)

*“I don’t think he could be anywhere better. He’s given the care that he needs.”
(Olivia, wife)*

*“I’m really impressed and I think the home has done her a world of good.”
(Jonathan, son)*

There were many complimentary comments about different aspects of the home, however, as is discussed below, a small minority of relatives were more critical and their comments

were more supportive of those of people with dementia and the video and observational data, suggesting that people with dementia were disempowered in relation to some aspects of care. These relatives were very clear in their ideas of what was missing and what was needed.

Views about care staff

Unlike residents interviewed, the majority of relatives spoke very favourably of care staff and also of other staff in the home such as domestics. They were described to be very caring, gentle, understanding and dedicated and on the whole, resident/staff rapport was considered to be very good:

“They are remarkable staff – wonderful staff, from the top right the way down to the domestics and the kitchen staff – everybody is very, very caring.” (Sophie, wife)

“The best thing has got to be the carers. I think they are the best thing, because without them it’s just a building. They are in the main very good.” (Nathan, son)

“Marvellous, I can’t fault them. They are very gentle, very caring as I said, very dedicated, I can’t say anymore.” (Olivia, wife)

The volunteers were also thought to be excellent:

“There are some wonderful volunteers here.” (Sophie, wife)

However a few relatives were more critical of staff, for example a daughter, Rachel, who was particularly critical of the home discussed her relationships or rather non-relationships with staff. She said that she did not always find it easy to approach them and described a barrier between staff and relatives, which she felt could sometimes impede communication.

“There’s like a gaggle of nurses who are all talking to each other. If you interrupt them, they don’t like it. You get the impression that the nurses are a bit separate,

they're a bit snooty...There's a barrier between the people – the families and the hierarchy – the head of home.” (Rachel, daughter)

This comment reflects perceptions of people with dementia who also described finding staff difficult to approach, as they always seemed to be busy doing other things. A barrier or distinction was also suggested, e.g. the resident quoted earlier who referred to staff as “them” and residents as “us,” which supports earlier suggestions that partnership working was not promoted within the residential settings.

Additionally, staff were not always very keen to help. Rachel felt brushed off as staff would claim it was not their duty to help, but another person's.

*“When you go to ask somebody to look after you mother, it has to be somebody who's from the third floor – she's on the third floor.....If you say 'oh my mother's soiled herself, can you help?' 'Oh I can't do it, I'm not from the third floor.’”
(Rachel, daughter)*

Information about her mother's welfare was never very forthcoming as she did not know where to go to obtain the information; there did not seem to be a file she could look at and she did not know who to approach:

“When you come here, if you ask how you mother was at night, no one can tell you because they're a different shift...There isn't a file that I can access – nothing that I can look at.” (Rachel, daughter)

These comments are again consistent with those of people with dementia who described staff as too busy to stop, talk, listen and address their needs and suggest that relatives may sometimes have felt disempowered as they were not always provided with adequate information and involved in what was going on.

Rachel described an incident when it was thought that her mother had broken her wrist and she had been taken to hospital, but nobody had thought to phone to inform her of the outcome:

"We never heard a thing. The home never phoned us...no one had thought to phone me up and tell me whether my mother had broken her arm or...they weren't sure if she'd broken it. I still don't know. I've not seen any report on it. I've not seen anything." (Rachel, daughter)

In addition, she described staff as talking among themselves in groups rather than attending to residents, and not doing much if a senior was not present, other than giving out injections etc. They did not seem interested in talking to and interacting with residents:

"When the head of home is not there, the carers don't work terribly hard. They all stand around talking to each other...There's loads of staff here, but where are they? They're all sitting in the office...a lot of the nurses are sitting together in the office waiting for something, like giving someone an injection. So maybe they're paying out too much on the qualified staff and they could do with more ordinary friendly people as carers." (Rachel, daughter)

This again refers to care being very task orientated, concerned only with basic care tasks, like feeding, bathing and administering injections and not with social and emotional needs. Rachel's comments support views and feelings of people with dementia and the video and observational data which also revealed a lack of rapport, interaction and communication between residents and staff. Staff were too busy attending to tasks around the home, or talking among themselves.

Levels of supervision

Relatives were generally pleased with the numbers of staff and subsequent high levels of supervision in the homes, which was an important issue for them. They described becoming increasingly concerned for the safety and wellbeing of their relative with dementia before their admission into the home and the knowledge that they were supervised all day, every day was very comforting. One relative, when describing how his mother had begun to neglect herself in the sense that she would not always eat and who had become increasingly concerned for her safety in her flat, commented:

“It’s nice to know that people are about to keep an eye on her, and make sure she eats. She has very good treatment here, because when it was left to her she just neglected herself, so I suppose the fact that she’s being looked after really, it’s a comfort, you know.” (Adam, son)

Other comments included:

“She gets 24 hour attention that she couldn’t get anywhere else.” (Benjamin, son)

“When she was at home she was taking the wrong pills, at the wrong times. At least here she’s getting the medical care as well as the back up care.” (Emma, daughter)

“It was a great relief that she was somewhere safe and where people would understand.” (Joel, son)

However, there were a few relatives who were more critical. In contrast to the relatives who described high levels of supervision, a particular concern for them was the lack of staff, for example, Rachel, the daughter of one resident, commented:

“There’s plenty of staff around during the day – you can’t imagine the difference at night. There’s one per floor at night. There’re four floors and there’s a supervisor downstairs – a nurse supervisor, who’s supposed to patrol once an hour – so what’s going to happen in an hour?” (Rachel, daughter)

The lack of night staff was a particular concern for Rachel, as she believed her mother had been abused by a night carer which she felt may not have happened had there been adequate supervision. She spoke of her anger and disappointment in the home as well as her fear for her mother:

“Well, I thought I was sending her to a place of safety, because we used to say: ‘Oh she’s on her own in the house’ – worried about her being on her own at night. I’m

more worried about her being on her own at night here now. So, not a place of safety...what you see during the day isn't what you get at night." (Rachel, daughter)

She spoke about the home's denial that anything had happened and of their lack of support, help and co-operation and of being constantly fobbed off:

"I haven't found the home very helpful at all. It's like them and us, they're trying to cover themselves, you know, covered up what they're doing." (Rachel, daughter)

She also criticised the home for not consulting her mother, although she had initially made the allegation:

"With all these counselling things, what I couldn't understand was why couldn't they have got someone to talk to my mother - an expert in the field?" (Rachel, daughter)

This relates to earlier discussion about the views of people with dementia often being ignored or omitted, because they are thought to be invalid which may make them very vulnerable to situations of abuse. The behaviours and attitudes of the home may have resulted in Rachel and her mother feeling very powerless, as nobody was taking on board their views and opinions and they had very little involvement or say. A few other relatives also spoke of serious incidents not being properly investigated by homes.

A couple of relatives thought there should be more day time staff as well, because of the high dependency levels and for safety reasons:

"I think there could be more staff because there are so many people that are completely dependent. Sometimes it needs two people to attend to one person for toileting or if they fall or at meal times or moving them and it means that there is nobody supervising." (Sophie, wife)

Perceptions that there were a lack of staff were supported by the video and observational data and also by comments of people with dementia. On several occasions there were no

staff members visible in the communal lounges. Staff were present in the home, but busy doing other things, rather than supervising or attending to the needs of residents. Video and observational data revealed several instances of residents shouting for attention and help, but no one was in sight to hear or respond to them. Residents' comments relating to carers having insufficient time to talk or listen also suggest that the levels of staff may have been inadequate on occasion. Insufficient or unavailability of staff may be an explanation for some of the disempowering practices described and observed, as perhaps staff did not have the time or were not present to build relationships, communicate and consult with people with dementia and their relatives.

Stimulation and activity

In contrast to the video observations and the accounts of residents, the majority of relatives believed that opportunities for and levels of activity and stimulation were relatively high. Typical comments included:

“They have therapy, they have music, they do a lot to keep them going. There’s a great deal of thought gone into it - that’s why I wanted him there – he’s in good hands.” (Olivia, wife)

However, there were again a few relatives who were more critical about this aspect of quality of care and arguably more concerned about quality of life and autonomy. In support of residents' views and the video and observational data, they described a lack of stimulation. For instance, Sophie, the wife of a resident who spent a considerable amount of time in the home, felt that there was not enough stimulation in the way of activity and interaction for residents and she felt that staff could perhaps take more time to communicate with residents:

“There are long periods where people just sit and I thought they were at a more advanced stage than they are, but when you actually sit and talk to them you get a response from them. I feel that the carers could maybe – when they’ve got an odd moment talk to some of the residents – some do – it’s not everybody. Maybe they

don't feel like talking at that particular moment, but I do think maybe more activities could take place.” (Sophie, wife)

This comment is consistent with perceptions of people with dementia and the video and observational data, as interaction between staff and residents and activity was observed and described to be minimal.

Sophie also suggested that there could be reading material made available, such as newspapers and magazines for residents, as she sometimes saw them actively seeking out stimulation and felt they may be bored, as they did indicate:

“People could pick them up or look at them, even if they don't know what they're looking at. Some of them can read, some of them do – because I see them looking at the posters on the walls sometimes and I see them reading the words. I have a blouse which has the names of towns all over it and I sometimes see them picking out the names of the towns so there are ways in which I think they could be more stimulated.” (Sophie, wife)

A couple of relatives who had previous experience of other homes were able to make comparisons between homes. A relative, whose mother had been in a much smaller home previously, where she had received much more one to one contact with carers and stimulation, commented:

“The care was wonderful, it was really 1-1. In fact as I recall it, every time I visited my mother there were two nurses on hand just for her and they used to take her for walks, they used to read the newspaper to her, they talked to her all day. It was wonderful, absolutely wonderful, they kept her stimulated, the attention was tremendous. Here, with the larger numbers it's much more difficult to give that kind of 1-1 relationship. The activity occurs perhaps once a week – music therapy, once a week art, once a week some kind of physical activity like dancing or whatever, so it's one afternoon a week instead of every day, two or three times a day. It must be because they've got so much heavier burden here, with so many more patients...I would like to see more stimulation – obviously the more

stimulation she has, the slower is going to be the deterioration in her condition.”
(Joel, son)

According to Joel, moving to a larger home had a negative impact on his mother’s quality of life. His comments suggest that smaller homes with higher staff to resident ratios may be more suitable for people with dementia, as they have the potential to offer higher levels of stimulation and one-to-one contact, and thus a better quality of life. Joel felt that stimulation was an important issue:

“You feel that if there was more stimulation then she’d perhaps lead a better quality of life than she is living now.” (Joel, son)

A friend of another resident also compared the home to one in which her friend had been previously and commented that activity and stimulation were much reduced:

“There they took them out twice a week, here she’s been out twice since she’s been here - more or less they sit in the corner and be quiet.” (Leah, friend)

These comments reflect the views of people with dementia and the observational data. There were few outings and activities and little contact with other people, which often resulted in a lower level of quality of life than expected.

Physical aspects of homes

In keeping with the positive comments of the majority of relatives about the quality of care provided, many of the physical aspects of homes were complimented. The location of the home was a plus point for some if it was near by, as relatives did not have to travel far to visit:

“Well it’s convenient – it’s on bus routes.” (Rachel, daughter)

The homes were praised for their warmth and cleanliness. Much effort was expended to ensure that homes were cleaned every day and sometimes twice a day and homes were always kept very warm, in fact on occasions residents would complain it was too hot.

“The cleanliness, the hygiene, everything is spotless. It’s very warm, it’s kept very warm because old people in that condition feel the cold. My husband hates the cold.” (Olivia, wife)

Supporting perceptions of people with dementia, homes were thought to be well decorated. Suggesting higher levels of empowerment at the level of the organisational, residents and family members were given some choice in relation to the décor and colours in their rooms and were encouraged to bring in photographs and other items to personalise them.

“When it comes to the environment and decorations, they’re one of taste. I think this is a very nice room - it’s certainly very acceptable.” (Samuel, son)

“He’s got a lovely room, which they decorated for him, when he went in you know and everything is sort of right - they’ve done it beautifully. The curtains match, the bedspread matches and it’s a very, very nice room – very comfortable. You’ve got a beautiful bed and armchairs, a basin.” (Olivia, wife)

However, a few relatives were more critical of the physical dimensions of homes, for instance, there were suggestions that perhaps padding could be put onto walls to prevent residents from injuring themselves, if they accidentally walked into them:

“There was a time when he used to be walking into walls and things and I used to say can’t you put things on the walls and I do think that for other people, I see problems.” (Sophie, wife)

It was also suggested that space could be better utilised. A few of the homes were especially large and there was much open and vacant space.

“I think they’ve wasted space...they could have utilised the space better.” (Sophie, wife)

In addition, it may have been difficult for people with dementia to orientate themselves and find their way around in large spaces and rooms. As some of their comments suggested, they may have felt lost and confused. On the other hand, large spaces may have been preferred by some who liked to walk. One particularly large home had a long circular pathway, which weaved around the floor and a few residents were observed to walk around and around all day.

Physical aspects of care

The majority of next of kin were also content with the physical aspects of care. In contrast to comments of people with dementia, the food was complimented by most relatives. As mentioned, residents were usually provided with a three course meal and food was observed to be well presented:

“The food is excellent, unfortunately, my poor mother, she doesn’t appreciate it, but it is excellent, and sometimes it’s all left.” (Rachel, daughter)

Homes were described as being well organised. Each home had a care routine, as residents would be woken and dressed between six thirty and nine o’clock; breakfast would be served at about nine o’clock and lunch at 12.30, before which residents would be toileted. They would be given tea at about three o’clock and an evening meal between five and six o’clock and then gradually taken off to bed. To relatives the home may have appeared to ‘run like clockwork.’

“The home itself, it really is run like silk – it’s run very well. There are many things I like...meal times are regular. They don’t seem to slip up anywhere. They’re not rigid. I don’t see how it could be any better run. No, I really don’t. I like the sweetness of it – they all seem to know exactly what they’re doing, why and how. It’s not haphazard – there’s nothing haphazard, it’s organised, very well organised.” (Olivia, wife)

Although homes may have run like clockwork, comments of people with dementia and the video and observational data suggest that the rigid routines and systems may have resulted in a lack of choice and autonomy and may be an explanation for some of the disempowering practices described.

Olivia also thought the personal and health care provided was very good and this was the perception of the majority of relatives:

He's manicured and they've got a hairdresser there and he's spotlessly clean, he's well nourished, he's looked after, doctors come 2 or 3 times a week, chiropodists, even the dentist – they'll take him to the dentist.” (Olivia, wife)

And the “Jewishness” of homes was an important factor for many:

“Because we're Orthodox Jews, it's important that it's a Jewish home – that's important.” (Sophie, wife)

“I chose Jewish Care because my mother would want to be in a Jewish place and uh, keeping a kosher home is central to her way of life.” (Samuel, son)

The physical environment and aspects of care were very important to many relatives but social and emotional aspects of care sometimes seemed to be less of a concern. As long as the home was clean, warm, well decorated and maintained and the person with dementia was fed and washed, many relatives were content. Perhaps they assumed that social care provided was just as good, but as they were not present in the home to observe it, they did not comment on it.

There were however a few relatives who were more critical about the physical aspects of care. In contrast to many relatives who believed homes were very well organised, it was thought by some that the homes could be better organised which may then improve quality of care for residents. Rachel who as mentioned was particularly critical of the home, partly

the result of a bad experience, described her mother as only being taken to the toilet at certain times, not necessarily when she wanted to go:

“I’m not sure the place is properly organised, quite honestly. The people here, you’ll see, they only take them to the toilet at certain times of the day, so if they ask in between they’re ignored.” (Rachel, daughter)

This supports earlier suggestions that the inflexible routines within homes could be disempowering for people with dementia and is a typical example of institutional care. Care is regimented, things take place at particular times and there is a lack of flexibility and residents’ wishes are not taken into account. Nursing and care staff have the power to make decisions and residents have very little:

“Things are done to her and she accepts it, she’s institutionalised.” (Benjamin, son)

These comments reflect those of people with dementia and the video and observational data which suggested that the levels of choice and independence in homes were minimal.

Medical, dental and optical care were criticised by a few relatives. It was thought that checks could be more regular, as on occasion residents had no teeth, or perhaps their eyesight had deteriorated but they had not seen a dentist or an optician. They were sometimes on a long list on which there had to be a certain number of residents requiring a check-up, before the dentist or optician would come out to the home. The son of one resident commented:

“She hasn’t got any teeth, she did have but she’s lost them. I keep saying she needs to see the dentist and I keep being told she’s on the list...and I get the impression the dentist will not come here for one person – the dentist won’t until there’s a dozen to see at one time...I don’t believe there are regular health checks – spontaneous health checks. I don’t think they do this on a regular basis.” (Benjamin, son)

These factors impinged on the individual's ability to be involved, in control and empowered and the lack of attention or concern reflects a lack of commitment to empowerment. Comments are consistent with perceptions of people with dementia and the video and observational data, which suggested there was a lack of choice and that individual needs were not always met. Other studies have also suggested that the levels of access to healthcare within homes are low, for example, Cohen-Mansfield and Lipson (2002), in a study exploring the detection of dental problems in people with dementia in nursing care, found that these were under-detected and under-treated and they suggest the need for improved training and care in this area. Similarly, Keller et al (2001) who explored the prevalence of eye examinations for people with dementia within nursing homes, found that these were infrequent. This may be a particularly important issue for people with dementia, as cognitive abilities, which include memory and communication skills, may be impaired and if there are additional difficulties with vision, hearing or speaking these problems could be accentuated. For instance, good vision is important to read non-verbal language and this may be especially important for someone with dementia who has more difficulty understanding what is being said. Likewise, good hearing and dental care are important for communication, as if a person has no teeth, it may be more difficult for someone to understand their speech. Good vision and hearing are also important to orientate oneself and, again, because a person with dementia may sometimes feel disorientated because of memory difficulties, these are especially important.

Other physical aspects of the quality of care also fell short of what was expected, for instance, it was suggested that there may be a lack of trained nursing staff in the home. One person described her friend falling and hurting herself and she did not think staff responded very competently. Additionally, medication was not always thought to be monitored properly:

"She went through a period of time, when we thought we'd lost her mentally completely, she wasn't herself. She was dull, lifeless, disinterested for months and she had been on some sort of medication, but I told them to take her off it and when they did the change in the way she behaved was dramatic and quick and people here couldn't get over it." (Benjamin, son)

There were complaints about clothing going astray or becoming mixed up with other residents' clothing, which may be expected, particularly in a larger home where there are many residents and all clothing is laundered together. Labels may sometimes be lost in the process of washing.

"Things go missing, not deliberately, but they go missing." (Emma, daughter)

"My Mum and Dad they came in with quite a lot of clothes all labelled up and suddenly we find them sort of wearing trousers or blouses or something that didn't belong to them." (Nathan, son)

Wearing unfamiliar clothes may have accentuated feelings of confusion and anxiety in the home and pervaded the individual's sense of esteem and identity.

Relatives also spoke about clothing not being ironed or washed and complained about the personal care received. People with dementia were not being looked after as well as relatives had expected and they or their clothes were dirty, which relatives did not like to see, especially if the person was previously very clean and smartly dressed.

"I think some of the basics could be improved, um, I don't think there's regular launder and cleaning of clothing. I don't believe anybody ever goes through the wardrobe to see if anything needs cleaning or washing. There are times that I come to see her and she's wearing clothes that are dirty and stained." (Benjamin, son)

A daughter described her mother looking like "a rag bag" in the home initially because she would insist on getting up very early and throwing on the same clothes that she had been wearing for several days, without having a wash. She was very resistant to staff helping her in any way and her daughter felt carers were not able to address this issue properly because of a lack of training:

"At the beginning I wasn't too happy, because she looked like a rag bag and she wasn't washed because she'd get up at 6 o'clock in the morning and get dressed. There weren't adequate trained staff to deal with her." (Emma, daughter)

This illustrates not only a lack of training and possibly some neglect, but also perhaps a dilemma on the part of care staff about the need to attend to personal care and also to empower the resident or maintain their autonomy. To accept help with tasks that the person had been accustomed to doing themselves for many, many years may have felt very degrading for the person with dementia and may have impacted negatively on their self esteem and self worth. Particularly if they were not always aware that there was anything “wrong” with them, it may have felt very shameful to be dressed and washed like a child and they may therefore have wanted to continue to do this for themselves. This may have been difficult for staff to explain to relatives, who expected their parent or spouse to be clean and well cared for and to be properly dressed when they visited.

There were a few instances where residents were observed not to be dressed very well, however this appeared to be largely dependent on the member of staff who had helped the person to get ready in the morning. Some paid greater attention and put in more effort than others. The numbers of staff available may also have been an issue, as this would inevitably have influenced the time expended helping each person.

The few relatives who were more critical raised a number of additional issues:

Specialist and EMI units

Specialist dementia units and EMI units received particular criticism and were thought to offer a particularly low quality of life. As the terms suggest, a dementia unit is a place particularly for people with dementia and an EMI (Elderly Mentally Infirm) unit is a place for older people who have mental health problems, including those with dementia. Some next of kin thought these to be unsuitable for their relative with dementia and this was particularly so if people with dementia were in earlier stages, because they had nobody to relate to, as others tended to be in more advanced stages of dementia. Additionally, being in such a unit was thought to accelerate the process of deterioration,

“I don’t think she’s as demented as some of the people here and I think she would have benefited from residential care as opposed to EMI care, as here she is with

people who are far, far worse than she is...There's nobody on her level, I mean her memory's gone, but she's not – I think she'll go that way, but she's not as demented...if there was just one person that she could relate to, it would be alright.” (Emma, daughter)

Other next of kin also thought that EMI units were inappropriate places for their relatives. Rachel's mother had initially been put in the EMI unit of the home and she described how demoralising and frightening this had been for her mother and she requested she be moved back down to the residential floor:

“When my mother came, she was quite with it, much more than she is now, but she was wandering a bit. They stuck her up in the unit – they locked her up there and we had to – we complained. There was nothing wrong with her...it was very demoralising for her up there. She would have deteriorated in about a month up there, because there are people up there, as you see, there are people who just scream and shout. She wanted to talk to people, she was talking to people for quite a long time...(Rachel, daughter)

This particular relative highlighted the importance of the person with dementia having somebody who could advocate for them, if they were not able to speak for themselves. Even if the person could communicate their needs and wants, their wishes were often disregarded, as it was thought that they did not know what they were talking about or what was best for them:

*“She would still be there now otherwise, because there's no one to say opposite, so unless you've got relatives, you could really be put in a really horrible situation.”
(Rachel, daughter)*

This again brings attention to the vulnerability of people with dementia, who are often disempowered, as their views and feelings are ignored by others. Comments are supported by the video and observational data and also by perceptions of people with dementia. Those residents in the EMI units described being particularly unhappy, especially those in earlier stages of dementia; there was even less to do and fewer people to talk to than on the

residential floors. Video and observational data revealed a dearth of activity and communication in these units; interaction of a social nature was rare and activity was very limited. Perhaps an aromotherapist or a dance or music therapist would visit once a fortnight, but other than this there was nothing to do, apart from watch the television.

Consistent with comments of residents, a few relatives spoke of people with dementia sometimes finding others with more advanced dementia, in the EMI units, strange or frightening:

She used to be frightened of them. She used to be frightened of their sort of - some of them have got strange facial expressions. She used to be frightened.” (Rachel, daughter)

Sometimes residents were also described to be irritated by the behaviour of others:

“She’d have a man next to her - he’d shout and she’d turn round and shout ‘shut up you stupid man’ and things like that...” (Nathan, son)

As mentioned, people in EMI units were much more likely to have more advanced dementia and it was not always easy for those in earlier stages to fit in and relate to others there.

Deterioration in condition

Other downsides of the home, expressed by a few relatives, included more rapid deterioration. Consistent with the literature, e.g. McDougall (1997), it was thought that being in a disempowering environment where dependency levels were high, there was little room for autonomy and minimal stimulation and contact with others, who were not always able to interact and relate with their relative, may have resulted in them losing their skills more quickly than they otherwise would have, e.g.

“Living in a place like this is a double edge sword and a necessity because the individual requires a certain caring you get here. The other side of the coin is, I think

you deteriorate quickly. I think her slow deterioration – much of it has been created by the fact that she's living in a place like this, surrounded by people who are not capable themselves and she's slipped into a syndrome.” (Benjamin, son)

“Unless the cells of the brain are exercised, they just lapse and if nobody talks to her from one day to the next she's going to lose the power of speech even faster...walking is extremely difficult, but if she doesn't walk at all, then she's going to become completely immobile, because she's not going to exercise.” (Joel, son)

These comments relating to high dependency levels and lack of activity are consistent with perceptions of people with dementia and the video and observational data, which also suggested a lack of autonomy and stimulation. They are examples of how a person's social environment can impact on their abilities and skills, affecting potential for empowerment at an individual level.

Institutionalisation

Institutionalisation, also reflected in comments of people with dementia and the observational and video data was mentioned by a few relatives as a negative aspect of being in the home. An institution is typically characterised by its strict organisation, rules and regulations. In such a setting, individuality, choice and independence are easily lost (Goffman, 1961) and this could be very disempowering for residents:

“I'm yet to be convinced that old age homes are anything but institutions, where people become institutionalised...that marks the beginning of the end...you need to be pretty strong to stand out in such circumstances...you walk in and there are rows of people sitting around...” (Benjamin, son)

“It's a warehousing place where people just sit and wait to die.” (Josh, cousin)

“She's institutionalised. I don't like that at all.” (David, husband)

These relatives held very negative impressions of homes. They saw them as depressing, oppressive places, containing batches of people, just sitting waiting for their turn to die. However, according to next of kin, the lack of good care was not attributable to it being low cost, in fact, the fees were thought to be excessively high for the quality of care received:

*“They make out they’ve got no money, yet the fees are astronomically high.”
(Rachel, daughter)*

Sometimes residents and their families were paying out substantial sums of money in order to fund care and expected a high quality service in return. Rachel was particularly unhappy with the care her mother was receiving in the home and did not consider it good value for money, for example, she felt the home could employ more staff and offer more stimulation.

(6.4) Implications of, and explanations for the discrepancies and similarities in views of relatives and people with dementia

The above discussion reveals a number of interesting findings. Firstly, on the whole, other than on a few issues relating to the physical environment, the majority of relatives’ perceptions of how people with dementia felt about the care they received and their own views were very different from residents’ own opinions of care. In the past, people with dementia have been disempowered, in that information about their feelings and views has been sought from relatives, while their views have been omitted or marginalised. However these findings challenge this approach, as they suggest that relatives may not always be aware of how people with dementia feel and it may be important to consult with individuals with dementia themselves.

This may be particularly important, since triangulation of data revealed that video and observational data supported comments of people with dementia, rather than the more positive views of the majority of next of kin. Most relatives described people with dementia liking the staff very much, however residents’ interview data and the video and observational data indicated that their relationships with staff were not so good as staff did not always listen or they were too busy to talk. According to many relatives the levels of activity were adequate, but people with dementia described a lack of activity and feeling

very bored. The video and observational data supported comments of people with dementia, as residents spent much of their day sitting doing very little and there was very little activity provided. These findings question the accuracy of relatives' perceptions of care and again challenge beliefs that relatives can represent the views of people with dementia and provide accurate information on services. They also suggest that obtaining accurate views from people with dementia, about services, is possible, which may be particularly important in the absence of reliable accounts from relatives.

There were however a minority of relatives who were more critical about the quality of care provided and their comments were better supported by those of people with dementia and the video and observational data. For instance they also described a lack of stimulation, choice and independence. Reasons for these more accurate views may be that these relatives tended to spend more time in the homes and therefore had better knowledge of what went on, had been through a bad experience with Jewish Care and were therefore more critical or had experience of other homes and were able to make comparisons.

There are a number of possible reasons for the more positive, but inaccurate views of the majority of relatives. Relatives on the whole were only present occasionally and for short of periods of time and they may not have had an accurate perception of what went on in the home, compared to residents or to somebody that was to spend a longer period of time in the home. Sometimes relatives said that they were no longer able to communicate with the person with dementia and they did not really know how they were feeling and were therefore only able to make statements based on their own experiences. Findings such as these again question the premise that relatives can represent the views and feelings of people with dementia. A few relatives disregarded anything negative said about the home by the person with dementia, as they thought that their illness meant they did not know what they were talking about, reflecting conventional beliefs that it is not possible to elicit reliable information from people with dementia. The daughter of a resident, when describing how much her mother had deteriorated over past years, commented:

"I don't like it sometimes, she says...she doesn't know what she's saying..."
(Emma, daughter)

She felt that her mother did not have much awareness or memory of what was happening around her anymore and her comments were therefore sometimes false or confused. Alternatively or additionally, believing that her mother's comments were inaccurate and she was happy may have been a coping strategy, easing her guilt about placing her mother in the home. Attitudes and beliefs such as these may impact on relatives' ability to speak on behalf of people with dementia or comment on the care they are receiving.

Additionally, when asked, many relatives said they had little or no input into care planning for their relative or much involvement in what went on in the home, reflecting disempowering practices within homes. Some relatives did not feel that their participation was important, for example the son of a resident with dementia felt his input was unnecessary if professionals were available and even thought that it may interfere in some way:

"I don't think I need have. I never have right from the very beginning, um, I think if you've got professionals you shouldn't interfere with them." (Nathan, son)

Considering the little time relatives spent in homes, their inability to communicate effectively with people with dementia, their lack of input into the care planning process and their dismissal of negative comments which they considered to be invalid, it is questionable how much knowledge they actually had about the home.

Additionally, some of the comments of relatives suggested that they may have been in denial of any adverse aspects of care, because it was too upsetting for them to think of their relative as unhappy and of they themselves having put them into that situation. Denial, which refers to denying the existence of something or that something is true, is a coping mechanism sometimes employed when a situation is too frightening or traumatic to confront. Many studies have shown denial among those facing difficult and painful situations (Wheeler and Lord, 1990; Finzen, 1990; Bahro et al, 1995; Katz et al, 2002; Teel, 2004). Denial may have impacted on relatives' ability to be objective about the care received and take on board any negative comments of people with dementia. It may have influenced the more positive views of relatives which were largely unsupported by video

and observational data, for example, a relative, when describing the pain and trauma she had experienced when her mother had been admitted into residential care commented:

“I have to tell myself that it’s okay – that it’s okay for her, that she’s adjusted as much as she’s going to adjust. Because if I didn’t let myself believe that it would be even harder, so I suppose to a certain extent I have to persuade myself that she is as okay as she’s going to be.” (Isabel, daughter)

When asked what it was like for her mother in the home, she replied:

“That’s ever so painful and hard really, because answering that requires me really to put myself in my mother’s shoes and really I think I’ve spent quite a bit of time trying to shield myself from thinking that way because I so hate the idea of her being unhappy.” (Isabel, daughter)

It was sometimes very difficult for relatives to think about what it was really like for the person with dementia in the home. Sometimes it was easier to convince themselves that the person was happy or believe that if the person talked about being unhappy, they were not really aware of what they were saying or their comments were confused. Chapter nine explores further the trauma and guilt sometimes experienced when placing a relative in a home. Other studies, such as that of Hagen (2001), also show that reaching this decision can be very difficult and ‘heart wrenching’ for relatives. Feelings of guilt may be accentuated in certain cultures such as Jewish culture where family have traditionally been obliged to care for unwell relatives within the home. Believing that their relative was happy may have been a way of coping with this very difficult and emotional decision.

Other reasons for the more positive views of relatives may include unawareness of the importance of social and emotional aspects of care for people with dementia. As discussed, residents referred to a lack of stimulation, choice and independence, however few relatives made reference to these issues; they were more concerned about the physical aspects of care, such as feeding and personal and medical care which were often described to be satisfactory. For example,

“I think the care is really excellent – she’s fed well, she’s clean, her room is kept nicely, if anything – she has a medical problem, they always phone me and I can’t really ask for much more than that.” (Benjamin, son)

It is possible that relatives did not always know what should or should not be in the home. Indeed some relatives did say that they did not know what they should expect, because they had nothing to compare with, having no prior experience of homes. They felt that a professional would be in a much better position to make judgements and comments about the quality of care provided. Below are comments of two relatives who other than their present experience of the home had no other to engage:

“I’m not in a position where I can compare it –see what goes on in other homes, because I’ve not experienced others – I have no precedence, I certainly think they’re doing their very best.” (Benjamin, son)

“I don’t have a great deal of experience with old age homes – I have no other experience to engage.” (Josh, cousin)

It was suggested by some that perhaps the care could be better, but it was as much as could be hoped for under the circumstances. Limitations were acknowledged, such as the numbers of staff and finances available:

“There’re limitations with amount of staff and everything what they could do, but from what I can see they’re doing everything. I mean I have no complaints about it.” (Benjamin, son)

“It’s about really as much as you can hope for. I mean if it was a private home, it might be a bit fancier, but I don’t think the care would be. It may be a bit more attentive, but I don’t think – I think they do everything they can do.” (Nathan, son)

There was a feeling that one should not expect too much or be too critical because everything was being done that could be with the resources that were available:

“You can’t expect everything to be absolutely perfect all the time. I think they do a fantastic job.” (Adam, son)

“Most aspects of this place are very good. It’s not easy – they’ve got quite a lot of people to look after.” (Josh, cousin)

“I’m not being critical of this home, because I think under the circumstances they’re doing their best – everything just boils down to money now doesn’t it really? Sad isn’t it?” (Nathan, son)

Nathan’s comment conflicts with those of a few relatives who described the fees to be very high. Perhaps there was sufficient money, but it was not expended on recruiting and training staff and on improving the quality of care provided, but on other things.

Additionally, relatives acknowledged that the job itself was not an easy one and often felt that they were not a position to criticise, as it was not a job they could easily do themselves. Many relatives had been caring for the person with dementia, prior to their admission into care, and they had been under a huge amount of stress and strain and had been unable to cope any longer. This issue will be explored further in chapter nine, but the narratives suggest that having given up their own responsibility of caring they had limited expectations of those whose professional role was to care for people with dementia.

“I can’t criticise these people you know. They’re only human beings. I wouldn’t for all the money in the world do their job.” (Nathan, son)

The people that have to do that job have an impossible task here. I suppose it’s the same anywhere, to look after the sort of people that live in a home like this had to be a vocation...This is an extremely difficult job....it’s stressful for them. It’s all very well for me to come marching in one day and say why isn’t this done and why isn’t that done?” (Benjamin, son)

Relatives were sometimes very grateful that there were homes and staff that could care for their relatives with dementia and were able to relieve them of their burden and their relief

and gratefulness may again have impaired their judgement and ability to see things objectively. The wife of a resident, who had been under a huge amount of stress and strain - at breaking point, before her husband was admitted into care, described what an invaluable source of support the home had been for her husband and her. She also believed that the care received by her husband in the home was much better than she herself could provide.

“They’ve saved not only my husband, but me...oh they’re wonderful...I can’t look after him the way all these people look after him.” (Olivia, wife)

Hagen (2001) found from his study that carers sometimes felt guilty they were not doing enough for their relative or not doing it well enough. Perhaps this had been an issue for Olivia, as it may have been for other relatives. The stresses of caring had been too much and she had felt unable to cope. Alternatively perhaps believing that care provided in the home was better than they themselves could provide was a way of relatives justifying placement of the person with dementia in the home; it was their way of coping with this decision.

Another relative had a busy life, as he worked full-time and he had a family and he did not want to have to worry too much about his mother, and so was very grateful for the support of the home:

“They’re great as far as I’m concerned. I’m talking as a son who really would like to live his own life a bit and not have to worry about my mother – so I’m grateful to them.” (Nathan, son)

(6.5) Discussion of findings

The results reveal that it is possible to elicit accurate views and feelings from individuals with dementia about the services they receive, suggesting that it is feasible to empower them at an individual level. Results indicated the mood scale and pictures to be helpful for some individuals and making links in words, building a good rapport and many of the other techniques described in chapter four were also useful.

Every effort was made to reduce bias and enhance dependability during data collection and analysis, however limitations of the methods should be acknowledged. With regard to collection of observational and video material, it is possible that some interactions and events were missed, during tape change or if they were outside the view of the camera which may have impacted on the findings. In addition, the results are based on analysis and interpretation of the researcher and again although efforts were made to monitor bias and maximise dependability, the stance of the researcher would inevitably have impacted on the research process. For example, I believed that communication with people with dementia is possible and made efforts to facilitate communication and find meanings in what was said. A different researcher with a different standpoint may have conducted the research in a different manner and hence obtained different results. It was considered that individuals in residential care were in later stages of dementia than those in day care centres, however, this was a subjective observation based on levels of memory and communication impairment perceived, as formal measures of the severity of dementia were not taken.

Although the findings indicated that it is possible to empower people with dementia, results revealed that external factors hindered levels of empowerment and resulted in people with dementia and sometimes their relatives feeling disempowered within the homes. These mainly related to practices and attitudes at an organisational/professional level, which impacted on empowerment at all levels, adversely affecting self-esteem, levels of involvement and consultation and quality of life. Residents described a lack of choice, independence, and communication, although they spoke of some issues relating to the physical environment and levels of privacy as adequate. Consumerist and empowerment approaches to involvement were discussed in an earlier chapter, however residents hardly had opportunity for involvement at a consumerist level, let alone at an empowerment level, as there was very little room for residents to make basic choices; and they certainly were not included in key decision-making or in the overall running of the home.

In contrast to perceptions of people with dementia, most next of kin were more positive about the quality of care received and felt that people with dementia perceived services much more positively than they indicated. Their comments suggest the levels of empowerment to be higher than those described by people with dementia. These

discrepancies between the views of people with dementia and the majority of their next of kin suggest that relatives may not always be aware of how the person with dementia feels. Many next of kin did say they did not know how their relative felt about all aspects of the care they received, or felt the person with dementia did not have enough awareness of what was happening around them to have many views anymore. In the past, people with dementia have been disempowered, as their views have been omitted, while relatives have been asked to comment on their behalf. However results suggest that relatives' perceptions may not be reliable indicators of how the person with dementia feels and that it is important to consult with people with dementia themselves.

It has been argued that information that is elicited from people with dementia through interviews may not always be reliable because of cognitive impairment, such as memory and communication problems (Brooker, 1999; Sarvimaki, 1999). For this reason, it has been argued that more importance or value should be attached to the perceptions of relatives. However, this chapter demonstrated that obtaining accurate views from people with dementia is possible, if appropriate techniques are used. Many very clear opinions and feelings were elicited, the majority of which were supported by the observational and video data. These did not however support the perceptions of the majority of relatives, findings which challenge conventional beliefs that comments of people with dementia are unreliable and highlight the importance of seeking their views and feelings, rather than relying on those of their relatives.

A number of reasons were identified for inaccuracies in relatives' perceptions. These included limited contact with the person with dementia and the home, having no prior experience of homes and thus nothing to compare with, being grateful for the support received and denial of adverse aspects of care. A few relatives who tended to spend more time in homes; have prior experience of services; were able to make comparisons; or had a bad experience within the home, were more critical of services and their comments were more supportive of perceptions of people with dementia and the video and observational data. A lack of choice, independence, stimulation and institutionalisation were mentioned particularly. They also commented on the lack of staff, poor access to healthcare, poor personal care and hygiene, excessive fees, disorganisation and a lack of communication, which not only related to interactions between staff and residents, but also to those between

relatives and staff. Difficulties with staff-relative communication may have impacted on levels of empowerment at a service-user power level, affecting the levels of involvement of and consultation with relatives.

Results of this phase of the study suggest that there is room for much improvement in care provided in residential and nursing homes, as reflecting accounts in the wider literature (Goffman, 1961, Sidenvall, 1999; Mitty, 2005), practices described and observed were very institutionalised and disempowering. These findings contrast sharply with results from the day care phase, which are discussed in the next chapter.

7 PERCEPTIONS OF DAY CARE

Having explored the experiences of people with dementia and relatives about residential care, this chapter examines quality of care within day care services, from the perspectives of people with dementia and their relatives. There is often an assumption that community care is better than institutional forms of care and it was therefore thought that aspects of good practice may be identified which may be transferable to residential settings.

Jewish Care owns and runs two different types of day care centres. There are five Community Day Centres (CDCs), which are open to all Jewish people who are over pensionable age. Most of these centres accommodate between 100-200 members per day and members either self-refer by turning up at the centre and registering, while others are referred via social services and other gate-keeping professionals, both in-house to Jewish Care and from local authorities. There are also five Special Day Centres (SDCs), aimed primarily at people requiring higher levels of care and supervision, the majority of who have a diagnosis of dementia. These centres differ from the community centres in that they are smaller, they cater for fewer people (normally between 20-30) and have a higher ratio of staff to members.

From a total of 159 members with a diagnosis of dementia within these centres, 16 were selected for inclusion in the study - eight members from the community centres and a further eight from the special day care centres. From these, ten consents were obtained from people with dementia and also from their next of kin, four of which were from people attending the community centres and six were from those attending special day care centres. Those from the community centres attended two out of the five centres, they all had a diagnosis of dementia and the gender ratio was split equally, in that two members were female and the other two were male. Two lived with their spouses, one member lived with his daughter and the last independently, but with much support from her daughter. Participants from special day care centres attended three out of the five centres, they all had a diagnosis of dementia and the gender ratio was again split equally, as three were male and

three female. Three members lived with a relative such as a spouse, son, daughter or cousin, one with a private carer and the other two members lived alone, although received regular support from relatives. Members with dementia were considered to be in earlier stages of dementia than participants in the residential phase.

Eliciting the views of people with dementia in this phase did not entail the use of pictures or the mood scale for the majority of participants. This was because participants, on the whole, were in earlier stages of dementia than those interviewed in the first phase of the project. However, it was still useful and effective to use the same type and structure of interview schedule, with open, broader questions. It was also important to allow the person with dementia to take the lead in any interview, to listen very carefully to what was being said, and pay close attention to body and non-verbal language. Building rapport with participants was also necessary and video and observational data again provided supplementary information and were cross-referenced with interview data in order to support the validity of interpretation.

In keeping with an aim of the study, which was that involvement should lead to personal development, or at least be directly beneficial to participants, a number of personal benefits for individuals were identified. For example, members enjoyed the opportunity to voice their views and feelings and meet and talk to new people:

“...it’s very nice of you to talk to me...I do like meeting new people.” (Ira)

“I enjoyed it...It makes a change that someone wants my opinion ...” (Enoch)

Mirroring results from the residential phase, findings reveal that it is possible to elicit accurate information from people with dementia, as many clear views and feelings were obtained and these were supported by the video and observational data; suggesting that it is possible to empower people with dementia at an individual level. In contrast to residential phase findings, the interview and observational data revealed factors at the level of the organisation to be more empowering which resulted in a higher level of empowerment at all levels, within day care services. Levels of communication, influence, control and quality of care generally were described and observed to be much higher than those in residential

settings. Special day care centres especially, were thought and observed to provide high quality of care for people with dementia, as they were particularly suitable for and able to meet the needs of people with dementia.

(7.1) Perceptions of day care centres

(7.1.1) Empowering practices at the level of the organisation

The perceptions of people with dementia and their relatives were largely positive (for a summary, see appendix VI). Nine of the ten members were satisfied with the care received and of these, seven, consisting of five special day centre members and two community centre members, were very positive about their experiences. They generally described a better quality of care than participants in residential settings, reflecting more empowering practices and systems at a professional/organisational level. Among other things, members described centres as stimulating, entertaining, friendly and hospitable, which are all important components of an empowering environment. Ira, who attended a centre one day a week, described it as a very welcoming place:

“It’s friendly hospitality.” (Ira)

Hannah, who attended four days a week, described her time spent at the centre as very stimulating and enjoyable:

“It’s a very nice place to come to. It keeps your mind active. There’re lots of nice people...no complaints about anything – pick us up, take us home, fed entertained – what more can I ask? Very, very nice – thrilled with it all” (Hannah).

Out of the three remaining members, no views were elicited about services from one person, although there were responses about other issues. The other two individuals both attended community centres and although they did not express dissatisfaction with the care received, were less positive about it, for example, when asked what it was like at the community centre she attended, one of these members replied:

"I suppose it makes a change." (Paige)

Similarly the majority of next of kin, that is eight out of the ten interviewed, were very satisfied with the services received, describing centres to be 'wonderful' places for their relatives, for instance, for making new friends. They described how much their relatives enjoyed attending,

"Oh it's wonderful here – wonderful. He's got so many friends here and he likes to talk to them and he loves coming here. He looks forward to coming here." (Sarah, wife)

"She loves it – she's very, very happy there. She tells me, she tells everybody that they make a fuss of her when it's her birthday. We order cake and everybody sings happy birthday and we have all the holidays and it's very, very nice for her" (Jeanette, daughter).

Out of the two remaining relatives, one person was a relative of somebody attending a community centre and her views were less positive; the other did not feel he had enough knowledge of the centre to comment.

Overall there were very few complaints about centres, particularly in relation to special day care centres:

"Oh I wouldn't like to complain because there's nothing to complain about – if there was something radically wrong I would complain." (Ira)

"Nothing bothers me. I think it's running very well. It's nice to come here." (Hannah)

Any negative remarks were relatively minor and related to issues such as parking or clothing becoming marked in art sessions:

*"I really have no complaints about it, except the parking – the parking is diabolical. Apart from that I think the place is superb. I cannot think of it being better."
(Robert, cousin)*

Additionally, a relative of somebody attending a special day care centre complained about the lack of space, which was a problem for his relative who liked to walk around much of the time:

"There's no place to move around in – it's very short of space." (Aaron, son)

Special day care centres were usually quite small, which suited many people with dementia who felt better orientated and not quite as lost as they may have done in a larger building, however smaller spaces did not work for everyone.

One relative, whose mother attended a CDC, was not altogether happy with the centre, as she felt her mother was lost among all the other people in this very large community centre and that she did not really participate in activities or talk to anyone:

"They thought that she would benefit from a smaller environment and I agree one hundred percent. She's just a total lost little soul there amongst all those people...She says she enjoys it, but I know she doesn't really join in with anything and when I've actually gone a bit earlier and I've seen her there, she always seems to be sitting on her own. She's never sitting talking to anybody...they said she would certainly benefit far more from a smaller environment..." (Amy, daughter)

The environment and care practices offered by community centres may have been less empowering for individuals with dementia than those of the special day care centres. Sometimes, because community centres tended to be much larger and more confusing; had a smaller staff to member ratio; and did not cater specifically for people with dementia, members with dementia were left feeling a little lost, less confident and perhaps they did not receive the attention that they needed. Additionally, staff in these centres did not have as much dementia training as those in special day care centres and may have been less able to relate to individuals with dementia. The quality of care for people with dementia in the

community care centres was generally considered to be lower than that offered by the special day care centres.

Positive interactions and relationships with other people

There were many aspects of CDCs and SDCs which were liked, for example, the other people such as staff, volunteers and fellow members were portrayed as very nice. Unlike participants in the residential and nursing phase of the project, nobody complained about a lack of interaction with people, and the consensus was that they were very friendly. There were very many positive remarks about staff, not only about the care staff, but about all types of staff at the centre, such as the transport and hairdressing staff:

“It’s very good because the people here are very nice. The staff are excellent...Even the people who take the money are very, very good....the office staff are very good...the hairdresser’s excellent” (Enoch).

“It’s absolutely superb. The people who work here are all pussy cats – they don’t lose their patience and they know their patients. I think the place is fantastic and the people are superb.” (Robert, cousin)

Members felt that they were treated with dignity and respect:

“Yes – generally – yes. The treatment you get here is very good, wonderful.” (Enoch)

Contrary to findings in residential care, there were no complaints that staff did not listen or want to interact or communicate, which suggests better rapport between members and carers and generally more empowering attitudes and practices at the level of the professional. Similarly, members reported positive interactions and relationships with other members:

“The other members are very good, yes, I find them okay.” (Hannah)

"I'm friendly with everybody." (Ira)

Although, as in residential care, very few people spoke of particular friends. Sometimes individuals were reluctant or even afraid to become attached to one particular person, should they stop attending for a some reason, perhaps because they had been referred to a special day care centre or had moved into residential care. One member, Hannah, described her reluctance to become too close to other members for this reason:

"It's no good getting favouritist because that one doesn't come, or that one's fed up or something. It's best really not to get too friendly, I find. Just be smiling to everybody, you know...you get friendly and they go or they don't come as many times as you – it gets complicated. I just like to smile and talk to everybody and that's it." (Hannah)

These findings are similar to results of Johnson and Troll's study (1994), which explored friendship patterns of older people and found that a few individuals were reluctant to become attached to others, because they thought they may soon die or leave them and they deliberately sought out friendships with younger people who were less likely to die before them. This was presumably was their way of coping with the potential distress of losing somebody who they had become very attached to and to some extent dependent on. In the same way, Hannah and other members may have avoided close friendships to avoid upset if the person(s) left the centre for some reason; keeping a distance from other members was a way of coping with possible hurt and distress and protecting themselves. The investment model of relationships (Rusbult, 1983) also provides an explanation for Hannah's comment and behaviour. This model suggests that the level of investment in or commitment to a relationship will depend on the perceived outcomes. Hannah may have felt that it was not worth her while investing so much of herself and energy into forming a close friendship with someone who may be leaving soon. Her remark suggests that she is speaking from experience and that people she had formed friendships with in the past had left the centre and she had not seen them again and she may have decided that forming friendships with others was not worth the upset and effort involved.

Video and observational data supported comments of people with dementia and their relatives, as in line with their perceptions, levels of interaction with staff and other members were observed to be high in comparison to those in the residential homes. Staff appeared to have more time to talk to members and interact with them socially; rapport was observed to be good; and members conversational and friendly with each other.

Higher levels of stimulation

The levels of stimulation were described to be higher than those in residential settings, which resulted in a better quality of life and a more positive experience for people with dementia. Generally, more activity was reported, although it was sometimes thought there could be a little more in CDCs or that the activity that existed in these centres was not suitable for people with dementia. One member remarked:

I think they could do with a bit more. A few more outings - that's my opinion."
(Paul)

When asked what he did at the community centre, another member replied:

"Well not really much you know." *(Enoch)*

In both of the community centres included in this study, there was a special activity for people with dementia, which consisted of a small transition group for people who experienced memory difficulties. Members of the group had usually been diagnosed with dementia and were about to be referred to a special day care centre, or on the waiting list of the special day care centre located nearest to them. However, this activity was observed to take place for an hour once or at most twice a week, which was not sufficient for individuals with dementia, again suggesting that quality of care provided in the community centres was inferior to that offered by special day care centres.

As would be expected, all activity in the SDCs was especially focused towards people with dementia. There was never any indication by members attending these centres or their relatives that there was insufficient activity or that it was inappropriate, as was sometimes

indicated by those attending community centres. This again relates to the special day care centres being more suitable for people with dementia. Hannah, who had been attending a special day care centre for about a year described how much she enjoyed her time at the centre. There were often discussions led by a facilitator or entertainers were invited in who she refers to as 'speakers.'

"I thoroughly enjoy it. Some days you have better speakers than others, but it's always very, very enjoyable." (Hannah)

Hannah's comment suggests that the nature of activity may have been important to members. People had different tastes and expected different levels of intellectual stimulation.

Video and observational data again supported perceptions and comments of people with dementia. Levels of activity were observed to be high in day care centres, particularly in the special day care centres, where a whole variety of activities were observed to take place, from speakers and entertainers, to painting, music, dominoes, cards and snooker. Activity within these centres was especially adapted to the needs of people with dementia and tended to take place within small groups, in contrast to the much larger groups within the community centres. This arrangement appeared to better suit people with dementia and allowed for higher levels of staff/member contact.

Higher levels of choice and independence

The narratives of people with dementia and their relatives suggest that there were more opportunities for influence and control in the day care centres than in the residential homes. For instance, there was some choice with regard to activities, as members were given the option of whether or not they wanted to participate and there were often a variety of activities and individuals could choose to take part in those that interested them:

"You don't have to do any of it. You can do what you wish" (Ira)

“They cater for different needs of people there. I think they have discussion, for whoever can understand, newspapers and what have you. My husband likes music, he always has so he enters into that and they have an art class today, which he never did before but he’s quite happy to do that which is good.” (Nina, wife).

With regard to food, usually two options were available for lunch and members could choose to have more if they wished. Individual needs were catered for and staff were described to be responsive to the needs and wants of members. Typical comments included:

“You can always have more if you wish, because I remember they always ask me do you want more?” (Hannah)

“I’m a diabetic so I have a diabetic cake. Sometimes I have salads and fish...I’ve noticed that if anybody goes to the staff and tells them what they want, they give it to them and it’s very good indeed.” (Enoch)

Although, members acknowledged that there may be limits to the choices that one could expect, with the number of members:

“Sometimes it’s very hard for them to please everybody.” (Enoch)

“I’ve got to eat it or leave it - there are too many of us to give choices of menu.” (Hannah)

Additionally, members felt they were relatively independent, as they were not told what to do and did not feel pressurised in any way:

“Independent? I like to be – like to think I’m independent...of course I would say that I’m independent in that there’s no one telling me what to do.” (Ira)

“Well it’s just a club – you can do what you want really. No one pressurises you.” (Hannah)

Members and their relatives did not feel frightened to complain, compared to informants in the residential phase of the study. They felt confident that their views would be listened to and enacted upon and did not feel that they or their relative would be affected or their care would be jeopardised in any way, suggesting more equal relationships/partnerships between members and staff. Typical comments included:

“No, not in the least. If I thought that I wouldn’t come. No, I’m very happy with the atmosphere here. I find them very friendly and fair. Fair – yes.” (Ira)

“I’d complain without a doubt – they’re very nice, they’re very helpful and very understanding, the people and I’d have no hesitations in saying anything I wanted to say about anything actually” (Jeanette, daughter).

If people said that they would not complain it was because they did not like to as they felt the service provided was excellent, or because they were not the sort of person to complain:

“I’m not a complainer and I wouldn’t complain if I felt they couldn’t put it right. But I’m a very organised person and if I see them doing it all wrong and nobody’s enjoying it and it’s taking them twice as long as it should, I wouldn’t tell them they’ve got to do it but I would suggest – it would be a lot easier if you did so and so...I come here to enjoy myself, but you can’t enjoy yourself if you’re upsetting people...” (Hannah)

“It would have to be very wrong and I’m a very reticent person to complain. I don’t like complaining. I very seldom complain – it would have to be something that I felt very strongly about – then I would complain..” (Ira)

Perceptions of people with dementia and their relatives were supported by the video and observational data, which revealed higher levels of influence and control within the centres. In keeping with their comments, members were observed to be offered choices in relation to activity, food and so on and appeared to be relatively independent in that that could go and sit where they wanted to, when they wanted to and engage in the activities they wished

to. They were generally observed to be relaxed, happy and comfortable with approaching staff about any issues.

Some of the more empowering practices identified in day care, particularly special day care centres could, with the right commitment and training, be possible in residential settings. However, day care practices were by no means perfect, as although levels of influence were higher and staff/member relationships possibly more equal than those identified in the homes, member involvement was consumerist and did not extend to involvement in the empowerment sense. Members were able to exercise choice, but there was little evidence of opportunities for involvement at a higher level, for example with regard to key decision-making and the planning and implementation of services.

Power imbalances

Although power relations were more balanced in day care than in residential care they were still tipped in favour of staff, particularly in the community centres, again suggesting lower levels of empowerment and less equal relationships within these centres. For example, sometimes members felt that staff needs were important and their own needs relatively unimportant and that they should take a back seat. One member, Miriam, who was asked for her views about aspects of the centre, continuously remarked that things were alright *“as long as it fits in with staff.”* She said that staff mostly selected the activities she took part in and when asked whether she would like to choose for herself, she replied:

“If the staff don’t mind.” (Miriam)

She felt that her needs were relatively unimportant. Another member, Jacob, felt that asking members’ views about services was a pointless exercise and that it was staff that were important and worth consulting. Perhaps these members had had little opportunity in their lives to make their own decisions and express their views. Someone else had always taken responsibility for this on their behalf, and they therefore found it difficult to express their perspectives. Another explanation could be that perhaps these members felt incompetent in some way. It is possible they had internalised other people’s restrictive views about people with dementia and perceived that they could not offer any valid views

or make their own decisions, reflecting low self-esteem and confidence, components which are important for empowerment at the individual dimension. Alternatively, in the case of Jacob, perhaps he could not remember very much about the centre at the time he was interviewed, or felt that he may be exposing himself if he did say anything, because he may not be able to remember everything. Perhaps he was avoiding this situation or covering up his problems by suggesting staff would be more appropriate to talk to. In Miriam's case, perhaps gender socialisation led her to belief that her needs were relatively unimportant. Miriam's husband said that decisions were mostly made for his wife, however he himself felt she was not in a position to make them herself:

"It's not something you can ask her – you want to go to the concert, you want to sit in this room or that room? She can't make her mind up." (Caleb, husband)

Sometimes, relatives and staff in CDCs and SDCs projected disempowering attitudes and views that people with dementia were somewhat incapable or incompetent, although not as frequently as in residential care, perhaps because of reduced stigma. Because people with dementia were in their earlier stages of dementia, they were perhaps perceived to be more capable than those people in residential care who tended to be in more advanced stages of dementia.

Transport

Other aspects of quality of care were considered to be excellent, for example, the transport was thought to be very efficient and drivers were described to be very thoughtful and helpful.

One member, Enoch, commented:

"I'm quite happy – the transport is very good indeed here. If anybody's in need or they have a fall –for instance I fell once in the van and she was very concerned, the driver. The drivers are excellent – they are excellent drivers – they make sure I'm okay when I get off the minibus...they help people that are in wheelchairs and can't help themselves – they look after them, make sure that everything is secure when

they go to their homes – they make sure that they are okay. Some of the patients that live here in the day centre, they let them have a ride with them and I think it's very good indeed and they take them home afterwards...” (Enoch)

The wife of another member, Sarah, described how dedicated the drivers were:

“They're so dedicated they really are – even the drivers – they help him down the steps and into the bus, you know. They bring him home and they take him right into the flat for me to make sure he's okay and I appreciate that...” (Sarah, wife)

Although on occasion transport was not available as there were no vacancies on the bus, or because individuals did not live within the catchment area. This was inconvenient for relatives who then had to drive fairly long distances to drop members off at the centre and then pick them up later on. It sometimes prevented members from attending the centre as frequently as they might had transport been available:

“The only thing is there's no transport and I work three days a week and you know there's nothing available at the moment, so I have to take her and pick her up...they said there was a waiting list and I didn't want her to wait, I was eager for her to go so um, I suppose they see once you start doing it yourself then you know.....” (Alana, daughter)

“No, I take him there. They've got a pick up service but it's only a local one. They won't come out here – it's too far.” (Nina, wife)

Physical environment

There was also some consensus that the physical environment was satisfactory, such as decoration, furnishings and colours:

“I think it's nice and bright and when you walk in there décor is nice and bright and cheerful really – yes I think that's nice, but it's all new there anyway.” (Nina, wife)

“I think it’s ideal...” (Aaron, son)

Although one or two relatives were not entirely happy. Relatives of members attending larger community centres felt that these were too big and that people with dementia would benefit from a smaller environment such as that offered by a special day care centre. The narratives of individuals within residential and day care settings suggest that smaller spaces were preferred and more empowering for people with dementia, who tended to feel less lost and more confident than when placed in a much larger environment.

Other remarks included those which related to the levels of privacy, which were thought to be adequate. People with dementia had the choice of some privacy at the centre if they wished:

“If you wanted to go and sit quietly by yourself somewhere you can do.”(Ira)

Although on the whole members did not want privacy, because often their reason for attending a centre was to socialise with other people. Comments relating to the costs of attending CDCs and SDCs were also positive, as services were thought to be good value for money,

“It’s excellent as it happens and they’re very reasonable – the hairdresser...It’s very reasonable. We pay £4.30 and it includes pickup in the morning, a cup of tea when he gets here and lunch now and a cup of tea again at about 2/3 and then they bring him home, so it’s very good value for money....” (Sarah, wife)

The perceptions of people with dementia and their relatives were again supported by the observational and video data. In line with their comments, special day care centres were observed to be much smaller than the community centres and better suited to the needs of people with dementia, who were observed to be a little lost in larger environments. The centres were on the whole bright, well decorated and comfortable and each had several rooms, so individuals could choose to sit quietly somewhere, if they wanted some privacy or time alone.

(7.1.2) Impact on the individual and service user power levels of empowerment

The empowering practices within the organisation, particularly within special day care services, impacted positively on individual wellbeing. As described, members talked about really enjoying coming to the centres, for example, Hannah, a special day care centre member, remarked:

It's terribly enjoyable. Yes, very good...I enjoy coming here. I think it's lovely. Breaks up my day. I really like it. (Hannah)

Unlike residents in the homes, members, particularly special day care centre members, appeared to be happy, confident, able to express their views, opinions and make their own choices. As described, communication between staff and members was good and nobody felt frightened to complain. Individuals perceived themselves to have a degree of influence and control.

In line with this and at a service user power level, the levels of influence and control held by individuals were higher than those in the residential settings. As described earlier, individuals had more opportunity to make their own choices and felt able to maintain their independence. Although, as mentioned, there was still some degree of power imbalance, particularly in the CDCs, where members at times appeared a little reluctant to express their views and wants. Additionally, involvement in both types of centre remained at a lower level, as members were not given the opportunity to get involved in higher decision making processes. Involvement was strictly of a consumerist nature.

(7.1.3) Therapeutic benefits of inclusion

Although opportunities to get involved at a higher level may have been lacking, the narratives of people with dementia and their relatives suggest that quality of life was enhanced by attending a day centre. Centres often played an integral role in meeting the social needs of people with dementia, for instance, Paul, a member attending a community

centre, who saw few people other than his wife at home, talked about the opportunities to meet and interact with new people at the centre:

“For me it’s wonderful. People meet people. People need the company of people. There’s nothing else to come here for. If the place was empty I wouldn’t come here.” (Paul)

Other generally representative comments included:

“It’s really to mix with people, otherwise he would just stay home and that’s no good.” (Aaron, son)

“It’s the only way of getting him socialising properly. That basically was the main reason and getting him to interact with people, which obviously was getting increasingly difficult.” (Nina, wife)

Opportunities to mix and socialise with people were particularly welcomed by those who experienced increasing isolation as their illness progressed. Contact with friends and sometimes family members decreased, as the deterioration was too distressing for them to see; they also did not always understand the illness or how to relate to the person with dementia and therefore distanced themselves. At home, people with dementia tended to see few others on a day-to-day basis, perhaps only their spouse, son or daughter with whom they were co-residing and if their children were working they were often left at home alone during the day. Sometimes individuals had lost a partner, which accentuated feelings of loneliness. Centres offered opportunities for inclusion by easing feelings of isolation through increasing social contact, although as described earlier in the chapter, some individuals chose to exclude themselves from the social networks within the centres, to some extent, because they were afraid of becoming too attached to people.

As described, attending a SDC was considered to be particularly beneficial. These centres were thought and also observed to provide an especially high quality of care, as they were particularly appropriate for people with dementia and better able to meet their needs than the community centres. CDCs were sometimes unable to cope with caring for individuals

with dementia; it was felt that individuals needed more support than could be offered by these centres; and/or would benefit from a smaller environment and a higher staffing ratio, which were offered by special day care centres. Therefore, shortly after a person attending a community centre had been diagnosed with dementia, plans were made to refer them on to a special day care centre. One relative, whose mother lived alone and had become very withdrawn since she had developed dementia, described her mother as being “swallowed up” in the larger community centre and receiving inadequate attention, because there were fewer staff.

“She was going to another centre and they were very good, but they phoned us up and said look, we feel that she’s not benefiting very much because she’s getting swallowed up. There’re only two or three carers for over a hundred people and they said she’s not getting the attention that she needs. We’d like to put her in a smaller place and that’s why she went to the special day care centre.” (Alana, daughter)

The son of another member who had previously attended a community centre, described his father as needing more support than that which could be provided by the community centre:

“He had been attending this other day centre which is just a normal day centre for retired people and then they said he was being disruptive because they would have entertainment and he’d get up and wander around - walking up to them, asking them questions and they couldn’t really handle him, so they suggested we take him to this special day care centre.” (Aaron, son)

In addition, people with dementia often described feeling bored at home, as there was sometimes very little to do, especially if they were alone. They were not always able to travel very far independently, to find means of occupying themselves or to visit friends and family and were stuck in the house much of the time. Reasons for this included reduced mobility or health problems. Staying at home doing nothing was also suggested to sometimes result in more rapid deterioration because skills were not used and were therefore lost. Therefore, attending a SDC or a CDC enhanced quality of life and well-

being by providing opportunities for stimulation, which were not always available at home. Relatives felt this was important,

“Well we thought it would be a nice day out for her – that it would be occupational therapy.” (Alana, daughter)

This was confirmed by the following individual, Hannah, who lived alone:

“I come five days a week. I enjoy everything – better than staying home bored to tears. It breaks up my day.” (member, Hannah)

Special day care centres, particularly, were thought to provide the right sort of stimulation and care as these centres catered specifically for people with dementia. Activities were focused towards people with dementia and staff trained to be able to communicate and relate well to members. A few next of kin described the positive effects that attending a special day care centre had had on their relatives, for example, one daughter, Jeanette, described her mother as more alert:

“She actually has been better since she’s been going there. I think she’s been more alert.” (Jeanette, daughter)

Other reasons for attending SDCs and CDCs included to provide a break for relatives or other people caring for the person with dementia which was sometimes described to be physically and psychologically exhausting and stressful. This will be discussed in chapter ten, but day care centres were an important source of support for informal carers and helped to enhance their quality of life:

“It’s to give the carers a break as well.” (Michelle, daughter)

The spouse of a member, Sarah, who spent much of her time at home caring for her husband, described how valuable the day centre was in enabling her to get out of the house and to pursue her own interests:

“I run a club for pensioners on Monday. I’m there all day, so it’s a great help that he’s here and it gives me an added interest” (Sarah, wife)

Another spouse, Caleb, who also spent most of his time caring for his wife with dementia, described how important the support of the day care centre was in providing an opportunity for a break from caring:

“One of the main reasons is to let me have a break – saves me looking after her for two or three hours.” (Caleb, husband)

Additionally, for the person with dementia, having the support of the day centre may have been empowering in the sense that it sometimes delayed admission into residential care, enabling that person to remain independent for a longer period of time. Had it not been for the centre, relatives may not have been able to cope with caring full time and people with dementia may not have been able to continue to live independently in their own homes. Jeanette remarked:

“The day centre is a major thing of support – major...otherwise she would probably have to go into a home if we didn’t have this sort of back up. I don’t know what would happen to her really.” (Jeanette, daughter)

Other reasons for centres being selected were because they were Jewish and catered especially for the needs of Jewish people, e.g. they provided kosher food and celebrated Jewish festivals. This was important as members felt more ‘at home’ and their religious and cultural needs were respected. Quality of life may have been reduced in another non-Jewish centre, which was not able to meet these needs:

“Because of the point of view of like the holidays, Jewish holidays and things like that - just so that hopefully it would jog something.” (Nicole, daughter)

Proximity and recommendation from others were also factors. It was certainly a bonus if centres were nearby as this reduced the time travelling back and forth.

“I heard about it from different people and through leaflets. It’s the nearest one to where I live. It takes 10 minutes to get here.” (Caleb, husband)

As mentioned, day care support enabled relatives to have a break from caring, so the last thing that they wanted, if they were responsible for transporting the person with dementia to and from the centre, was to spend an excessive amount of time travelling.

(7.2) Confirmability of views of day centre members and their relatives

Interview, video and observational data were again triangulated. The videotaped and observational material supported the views of people with dementia and this time also those of their relatives, again suggesting that what is said by people with dementia can be accurate and that it is possible for individuals with dementia to be empowered at an individual level. As described by people with dementia, practices and systems within centres were more empowering than those within the homes. Centres offered a better quality of care and the levels of activity, choice and independence were observed to be much higher. A structured programme of activity was observed to take place during the day, however this was not rigid. There was some flexibility, in that often two or more choices of activity were on offer at any one time and individuals could select from these, as described by people with dementia and their relatives. Although involvement tended to be of the consumerist, rather than the empowerment type, levels of influence and control were observed to be higher and there were more opportunities for choice and independence throughout the day. Levels of interaction with staff and fellow members were also viewed to be high and in contrast to the homes, members appeared to be enjoying their day.

In keeping with comments of people with dementia and their relatives, the environment offered by special day care centres was observed to be more appropriate and empowering for people with dementia than the community centres. Individuals sometimes appeared to be lost in the larger community centres. As in residential care, they were sitting for periods of time with little interaction and activities were occasionally observed to be unsuitable for them. In contrast and in line with comments of people with dementia and their next of kin, activity provided in special day care centres was especially adapted for people with dementia and staff who had more dementia training were better able to relate to members.

Special day care centres were much smaller, with fewer members which increased the potential for one to one staff/member contact. People with dementia, who were at times lost in the larger community centres and who may have found it more difficult to participate in larger groups, benefited from this environment. Also in keeping with perceptions of people with dementia and their relatives, centres were well decorated and opportunities for privacy were available if members wished to be alone.

(7.3) Consensus of views of people with dementia and next of kin

In this phase of the project, there was some consensus between the views of people with dementia and their relatives. Relatives' comments suggested that they had better insight into how people with dementia felt and more accurate knowledge about centres than relatives in the residential phase. This was despite the fact that relatives, for a variety of reasons, often had little knowledge about centres and what went on in them:

They were only present for short periods of time to drop their relative off and pick them up or perhaps they did not even do that, as transport was often available.

"I don't spend a lot of time there and he can't tell us about it." (Aaron, son)

"Well I don't really know what goes on there because I drop her and pick her up. I've never actually stayed there and seen what goes on, so I can't say." (Alana, daughter)

Day centres often provided the opportunity for relatives to have a break, so they did not want to have to spend a huge amount of time there, but used the day to get on with other things, like their daily chores or just spent the time relaxing,

"I don't usually come here because I've got quite enough to do. I've got a home to keep you know and on Thursday I do all my shopping and normally I go to the hairdressers, so each day I've got taken care of..." (Sarah, wife)

Sometimes the person with dementia could not remember very much about what they had done and what they thought about the centre when they got home and were questioned by their relatives:

“I’ve always asked him, did you have a good day? Um, yes, it wasn’t too bad. Did you have a good lunch? I don’t remember.” (Sarah, wife)

“It’s difficult for me to say because my husband can’t explain anything. I’ve never got any feedback from him, so that’s a difficult one for me to answer.” (Nina, wife)

On the whole, relatives had little input into what went on in the centres and very often did not attend care programme approach meetings or reviews held at special day care centres. The opportunity was usually there, however, it was not always taken up by relatives because they had other commitments. If they were in a full time caring role, then they felt they needed to take a break when they could, and not spend their time off going to various meetings.

“I’ve got lots of stuff now - it’s to do with me, because I must have some rest.” (Deborah, daughter)

“It’s not that no one asks me, it’s just really that I haven’t got the time to become involved.” (Jeanette, daughter)

There were no such meetings at the community centres and relatives had very little opportunity to get involved in care for their relative. Practices within the community day centres were generally less empowering for relatives as well as members. Alana, the daughter of one member, commented:

“I don’t honestly know what she does there, they don’t tell me what she does and she can’t remember what she does, so I’m just totally in the dark.” (Alana, daughter)

Although, she would have liked more input and knowledge about what went on in the centre:

“Yes I think that would be a very good idea actually. I would be very interested as to what she is doing there, or does she just sit all day, I don’t know - but yes I think it would be a very good idea to know what she is doing there.” (Alana, daughter)

However, from the little that their relative with dementia said about the centre; from their behaviour or their enthusiasm to attend; their manner when they returned; from small glimpses of centres; and from what they had heard from other people, next of kin seemed to think that their relatives were very happy there:

“He must enjoy it, otherwise he wouldn’t want to go, I’m sure of that. He would say I’m not going if he didn’t enjoy it.” (Nina, wife)

“It’s a known fact in the community that it’s a wonderful place there for elderly people – it’s supposed to be – it’s always known...” (Alana, daughter)

There could be a number of explanations for the consensus in opinion of people with dementia and their relatives. As mentioned, relatives had heard that centres were good places to go and people with dementia seemed enthusiastic to attend and happy when they returned. In addition, perhaps relatives in this phase found it easier to communicate with the person with dementia and to find out how they felt about various issues because the dementia was less advanced. Alternatively, given that relatives had limited knowledge about centres, perhaps the consensus was coincidental and relatives’ views were positive for reasons similar to those discussed in chapter six. Relatives perhaps were very grateful for the support received, or they did not know what should or should not be there, because they had no prior experience of centres and therefore nothing to compare with. Nina, the wife of a member commented:

“Well to be honest I wouldn’t know how to better it I don’t think because I’ve not run something like that. I don’t think I can really give you an answer to that. I think someone like you can probably see things more objectively at the centre than I can. I

do think an outsider could see things more easily – you're in a position to see it more objectively than I can – what should be done and what shouldn't be done. It's only like if the client were to complain or something that you'd get some feedback, but as I've not had any feedback I can't comment.” (Nina, wife)

(7.4) Discussion of findings

Mirroring results from the residential phase, results show that it is possible to elicit accurate views and feelings from people with dementia and it is therefore feasible for individuals with dementia to be empowered at an individual level - the various techniques used to enhance communication and empowerment were considered in chapter four. Limitations of this phase are similar to those of the residential phase. Although precautions were taken, it is possible that occasional events and interactions were missed by the video or researcher. In addition, my standpoint inevitably influenced the research process. I selected the methods employed/offered. A different person may have chosen to use different data collection techniques and thereby obtained different data. It is also possible that I made more efforts to communicate with individuals and find meanings in what was said than another person with a different standpoint would have, because I believed that communication with people with dementia is possible. With regard to the severity of dementia, individuals within day care centres were considered to be in earlier stages than those in residential homes, however, as in the residential phase, this was a subjective observation based on levels of memory and communication impairment perceived. Formal measures of the severity of dementia were not taken.

The results revealed that practices at the level of the organisation were more empowering than those within the residential settings. The quality of care and opportunities for influence and control, particularly in special day care centres were perceived and observed to be higher and interactions and relationships with staff and other members more positive. These resulted in better individual wellbeing, enhanced confidence, feelings of greater control and a higher quality of life. These differences may be explained in a number of ways. As members were generally in earlier stages of dementia, the stigma may have been less and therefore people with dementia may have been viewed as more competent and capable and offered more opportunity to make choices and decisions for themselves than

those in residential settings. The environment in the day centres included in this study may have been more empowering than that in residential settings, as there were fewer rules and regulations. In addition, staff did not have the same level of power over members, because they were not dependent on them for every aspect of their life; they went home at the end of the day and if they did not like the centre they did not have to attend.

An explanation for the higher levels of activity and the more positive relationships between staff and members in day centres could be that staff had more dementia training and training in person-centred approaches and therefore had better ability, skills and/or knowledge to communicate effectively with people with dementia. The job descriptions of day care staff also placed more emphasis on the provision of mental stimulation than the job descriptions of residential care staff, who often had a special activities co-ordinator to take on this role; perhaps only one for the entire home, which could be another reason for the higher levels of activity in day care settings. In addition, as people were on the whole in earlier stages of dementia than those in residential care, it may have been easier for staff to relate to and communicate with them.

Perceptions of community centres were less positive than those about special day care centres and quality of care not as high. People with dementia sometimes felt lost and isolated in the CDCs and their needs were not always met. This may reflect the community centres being larger than the special day care centres, with a smaller staff to member ratio. Additionally, unlike the special day care centres, there was no programme of activity adapted for people with dementia, as community centres catered for older Jewish people generally and not specifically for people with dementia. In fact if it was thought that someone had developed dementia, plans were made to refer them on to special day care as soon as possible. Staff in community centres did not have as much training to work with people with dementia and were therefore less likely to be able to relate well to them. During interviews conducted as part of the wider project (Vass et al, 2002), community care centre staff did mention that they had better relationships with those who were more communicative, talkative and friendly, which suggests they had difficulty with communicating with or relating to somebody with dementia, who was perhaps withdrawn and less socially active, as a result of confusion and communication difficulty.

Many of the practices in day care centres, particularly special day care centres, may be transferable to residential homes and community day care centres, and increase the potential for higher levels of interaction and empowerment. Although as mentioned, there was room for improvement in day care services as well. For instance, involvement in the centres tended to be of a consumerist, rather than an empowerment type, as choices were offered, but there was little opportunity for involvement at a higher level.

Triangulation of data obtained from different methods revealed that video and observational data again supported the opinions of people with dementia, yet again challenging conventional beliefs that what people with dementia have to say is invalid or false. In line with the comments of people with dementia, video and observational data revealed levels of activity, influence and control to be higher within the day care centres, particularly in the special day care centres. This time relatives' views were supported by those of people with dementia and the observational and video data, suggesting they had more knowledge about the centres and the feelings and perceptions of people with dementia. However a note of caution is needed, as relatives often had little knowledge of what went on in centres. Their positive views may reflect appreciation of the support they received and as in the residential phase, a few relatives also mentioned they found it difficult to be critical because they had limited experience of other centres and therefore little to compare with. These findings suggest that it is important to consult with people with dementia themselves.

8 EXPERIENCES OF PEOPLE WITH DEMENTIA OF THEIR ILLNESS

This chapter examines the experiences of all 27 residents and day care centre members of having dementia. It explores their feelings and views as described by themselves, revealed by the observational and video data and their relatives. Results show that with the onset and progression of dementia, individuals experienced many changes, which sometimes impacted adversely on self-esteem; on the way they were treated and perceived by others; on the levels of influence and control they had over their lives; and on their overall quality of life, which may have resulted in them feeling very disempowered. A particularly significant issue for many people with dementia was loss. For instance, individuals experienced loss of their independence, a loss of dignity, loss of memory and communication skills and as a result sometimes became depressed, angry or withdrawn. Self-confidence was also affected. Other experiences included confusion, bewilderment, fear and a constant need for attention. There were a number of different methods of coping, for example using memory aids, covering up mistakes and lack of knowledge, withdrawing from situations and denial.

Personal benefits for participants with dementia are similar to those described in previous chapters, as the participant group was the same. Limitations of this part of the study relate to the amount of information gathered from people with dementia. Although many experiences about dementia were obtained, these were slightly restricted, as none of the individuals were aware of their diagnosis or were perhaps in denial of it. Relatives' narratives and video and observational data were therefore used to supplement these data. The rationale behind this may be questioned, as findings from the residential and possibly day care phases of the project revealed that relatives had limited knowledge about the feelings of people with dementia. However, in this chapter, relatives' comments are mostly based on their observations of and interactions with people with dementia when they were living at home, where relatives generally had more contact with the person with dementia, than in the day centres and residential homes. Communication with people with dementia,

which was sometimes difficult in the residential settings, was also probably easier since individuals tended to be in earlier stages of dementia. It is therefore considered that relatives' perceptions may be more accurate.

In addition, although precautionary measures were taken and efforts were made to reduce bias and enhance credibility, it is possible that the video and observational data did not reflect all that happened. As mentioned in previous chapters, perhaps some events and interactions were missed, because they took place outside the view of the camera or the researcher was not present for a short period of time, which may have impacted on the findings. The standpoint of the researcher should also be mentioned as this may have influenced the results. Because I believed that communicating with people with dementia is feasible and there is meaning in what is said, I may have made extra efforts while interviewing people with dementia and while interpreting data, which another researcher with a different standpoint may not have done.

(8.1) Experiences of dementia and impact on the individual level

Changes in cognition and emotion

Changes in cognition and emotion were sometimes a cause of distress and frustration and may have felt very disempowering at the level of the individual, for example, for Stephanie, quoted below:

“I don't know where my head is, it's driving me mad.” (Stephanie)

All participants experienced memory problems. Sometimes these presented no particular problem and were attributed to the ageing process, perhaps because individuals were not aware of their diagnosis, having forgotten, or they had not been told of it:

“I forget a lot. It's never been like that – I can't help it, it's the age.” (Joanna)

“I forget what I’m trying to remember...but I make the most of it...I suppose when you get to a certain age, you do lose your memory – we all do that, so I make the most of it.” (Ira)

“Sometimes I forget – it’s old age.” (Paul)

Joanna was unconcerned about being unable to remember recent events, as she did not think these were worth remembering. She described having had an active and happy life until recent years. But now, as a result of the dementia and also mobility problems, she was not able to do the things she enjoyed in life. Therefore, recent memories had become unimportant, and she was happy to live in the past:

“Nothing special what I forget. I know exactly what I have done when I was younger.” (Joanna)

Other people were more worried about the difficulties they were experiencing and their comments suggest that they may have felt particularly disempowered. For example, they were sometimes reluctant or did not feel confident about speaking out because they thought they would look foolish or appear inadequate, when they could not remember words, names or events. Jessica, a very sociable person who liked to interact and be with people, now felt self-conscious in company and when articulating herself:

“Sometimes I feel a bit embarrassed. I should know that, but I just can’t get it. Yes it’s not serious, serious, but it’s enough to make me – because I’m always self-conscious.” (Jessica)

Several individuals with dementia were observed to be very quiet and withdrawn. It is possible that they too were aware of the difficulties they were experiencing and were reluctant to speak, in case what they said was not quite right or appeared odd.

In addition, memory problems sometimes resulted in feelings of disorientation and loss of control at an individual level. One resident, Stephanie, described feeling very bewildered and confused much of the time. She did not know why she was in the home or where

anything was or what her daughter looked like. The fluctuations she was experiencing in her memory were very frightening for her:

“I can’t remember anything. I can’t remember what my daughter looks like. Is my mother dead? Did she die? I can’t remember, I hope not. Where do I sleep? It’s like I’m a different person.” (Stephanie)

Video and observational data also suggested that individuals felt confused at times - wandering around, querying where they were, not knowing where things were in the home and so on. In addition, relatives related various incidents, for example, Dinah:

“You can talk to her about all sorts of things – she’s fine. But on a day to day basis she gets confused with the day, she gets confused with whether she’s eaten or not, whether she’s taken her tablets or not.” (Dinah, daughter)

Additionally, feelings of frustration were sometimes experienced. A relative, the daughter of a female resident, described her mother’s impatience, when she could not remember and recognise people in the magazines they sometimes looked through together. She thought her mother blamed herself, and believed that there was something wrong with her, which may be applicable to many of the individuals with dementia who were not aware of their diagnosis:

“I think once or twice she’s got angry with herself, because what I was doing was, I was sort of bringing in a magazine and pointing to the pictures. But she used to get impatient – she didn’t want to do it anymore, I think because she couldn’t recognise anybody.” (Rachel)

Memory difficulties may have impacted on self-confidence and self-esteem at the level of the individual and resulted in people with dementia feeling inadequate. Although the person with dementia was not always aware of their diagnosis, they usually realised that there was something wrong and were sometimes upset or distressed by it. Interviews with relatives and the video and observational data sometimes indicated individuals to become

more emotional, tearful, angry or aggressive towards other people or towards themselves. They sometimes asked if they would ever be 'normal' again.

Communication difficulties were also experienced. As mentioned, there were problems with remembering words and events, but those with more advanced dementia were not always able to communicate their feelings to others, which was a cause of distress:

“She knows in her heart and mind that there’s something wrong, but because of her disability, she can’t put it into words – she can’t say how she feels, or what is wrong – she has no idea, she has no concept...I think she’s very unhappy because she knows there’s something not right but she can’t simulate – she can’t get it together to know why things are happening.” (Joel, son)

It may have felt very disempowering, not to be able to articulate their wants and needs, particularly to those responsible for their care. As described in chapter six, the wishes and perspectives of individuals with dementia in the residential homes were often not heard or taken into account. There was generally little communication, which may partly have been attributable to communication difficulty between staff and residents. The video and observational data revealed instances where individuals were trying to communicate a message either verbally or non-verbally, but this was not picked up or the meaning was not understood, which may have left the person feeling very frustrated and distressed.

Other experiences, also affecting levels of empowerment at an individual level, included losing track of time. Individuals did not always know the time of day and what they had done or would be doing in the day, which may have resulted in low self-esteem and feelings of loss of control. A day centre member thought it was time to go home, but it was still morning. A resident did not know the time, day or year, although, it was probably very easy to lose track of time in the homes, as there was little to distinguish one day from the next and very little reason to remember the day or year. Next of kin also related various stories:

“She turned night into day and she’d be walking around her flat at all odd hours, turn up at meetings at the wrong time.” (Samuel, son)

Rachel described how her mother had arrived at her house in the middle of the night, all dressed for a wedding which was on the following day:

“In the middle of the night there was a banging on the door. It was about three o’clock in the morning. My son got up and said ‘God it’s grandma, she’s come for the wedding’ and she was all dressed up.” (Rachel, daughter)

Feelings of fear were also common, which may again have resulted in low self-esteem and perceived loss of influence at an individual level. Earlier in this chapter, a resident described how frightened she felt in the home and other residents were also observed to be feeling this way at times, sometimes tearful, distressed and even screaming and shouting on occasion. Next of kin also described various incidents when their relatives had been scared:

“My mother wouldn’t let anybody go out of the house. She wouldn’t let anyone leave her on her own - she wouldn’t - she used to scream absolutely petrified. She’d scream if we went out of the room.” (Rachel, daughter)

There were often constant pleas for attention and help:

“She was phoning the emergency doctor day and night.” (Rachel, daughter)

These experiences and feelings could well be explained as understandable reactions to what individuals were experiencing, rather than symptoms of the disease, suggested by Bender and Cheston (1997). For example, repeated requests for attention could stem from fear and bewilderment at what was happening to them and a need for reassurance and comfort. People with dementia were rarely provided with the opportunity to explore their experiences and to make sense of what was happening to them.

Individuals generally felt more empowered, confident, safe and orientated in familiar places and with familiar routines, which is probably applicable to most people, but more so to somebody with dementia who may find it difficult to orientate themselves and to learn new

things. Enoch, a member with early onset dementia who attended a community centre, described how frightened he sometimes felt when he went to new places. He thought that he may get lost:

“The only worry is when I go away anywhere, I get nervous because sometimes I forget. When I go I can’t always remember like I did years ago. I’m frightened of - I’d be alone and not know where I am.” (Enoch)

Leah, a friend of a resident, described her as sticking rigidly to the same routine or the same chair, again highlighting the importance of familiarity in helping the person with dementia to feel safe, secure and orientated in what they were doing and where they were:

“Now she likes to have the same chair, she knows exactly when it’s her tea time – she gets her cup of tea, she has lunch - so long as she’s got her bed and her regular routine, that’s all that she’s happy with.” (Leah, friend)

The video and observational data also revealed individuals with dementia to chose to sit in the same chair, at the same table in the dining room, with the same people and so on. Being in familiar places, with familiar people and having familiar routines enhanced feelings of self-confidence and control.

Changes in physical abilities

Loss of physical skills may also have disempowered people with dementia at an individual level, for example a loss of continence, which sometimes resulted in a loss of dignity and self-esteem. The daughter of one resident described her mother’s embarrassment when she soiled herself:

“...I think that was the first time it had happened –when I’d been there anyway and I think she just felt very ashamed...she didn’t want to see me - for me to see what had happened...she just shut herself away in her room...” (Rachel, daughter)

Sometimes the person's mobility and co-ordination had been affected. Sophie, the wife of one resident with advanced dementia, described how her husband's walking skills had deteriorated:

"He can't walk now and his co-ordination and balance is lost." (Sophie, wife)

This was sometimes a cause of upset and may have resulted in feelings of powerlessness. In a residential home, one man was repeatedly seen to attempt to stand up and walk by himself, but because his co-ordination had been affected he kept losing balance and falling, which must have been very frustrating for him. When care staff noticed this happening, they pushed him down in his chair and refused to let him get up, as presumably they were concerned for his safety. However, an alternative action could have been to help this man to walk by providing a crutch or acting as an escort, which may have helped him to maintain his independence and autonomy to some degree. Joanna talked about having to use a walking stick in recent years and how anguished she felt that people had started to stand up for her on the bus:

"I don't wear a stick anymore you know. The hospital gave me a stick, you must go with the stick and too many people got up for me, to give me a seat. It was too terrible for me. I said never again after a fortnight, I wear a stick - I've got three umbrellas. Now people don't stand up so much." (Joanna)

She also talked wistfully about her very active life before the home and when she was younger, which included gymnastics, swimming and climbing mountains.

Losing the ability to drive was often a source of extreme sadness, particularly for men, perhaps because not only had they lost a skill and with it their independence, but the ability to perform a gender role. For women, being unable to drive did not present such a problem. They were more concerned about being able to look after themselves and live independently. This finding is perhaps indicative of roles which these individuals had performed in the past. Men were perhaps accustomed to being 'looked after' by their wife or mother from a domestic point of view. The relative of one day centre member commented:

“...domestically speaking, he’s quite happy to let people do things for him – quite happy...but then you have to go back in his life – he’s always had someone doing these things for him...his wife and before that his girlfriends and then it was his aunt...” (Robert , cousin)

Their meals were cooked for them, washing done etc, whereas women carried out these tasks by themselves and looked after their husbands. Men were used to working outside the home, earning the money and also driving and so were more concerned about maintaining these skills. Losing this skill may have been very disempowering at the level of the individual, impacting on self-confidence and restricting autonomy. Individuals now had to rely on others to transport them to places they wanted to go. Nina described her husband’s distress:

“...he loved driving so much...I mean a lot of people just use it to get to A to B...that was the biggest loss. That was very, very difficult when he had to give that up – very hard.” (Nina, wife)

The losses experienced impacted on individual wellbeing. People with dementia sometimes became very depressed, for example, one resident, who had had a very active life before moving into the home, felt that she had nothing left. She had lost her home, her husband and family. When asked if she would feel comfortable to complain if there was anything wrong or if she did not like something in the home, she said that she did not care anymore and she wished she was dead.

“No, I don’t say anything – I couldn’t care less, because I’m in the situation – I couldn’t care whatever it is. The only thing is, I wouldn’t eat – I wouldn’t be here anymore. I wouldn’t live anymore.” (Katherine)

Alana, the daughter of a day centre member, described her mother’s depressed state. She felt her mother had almost given up on life, as she did not seem to want to do anything anymore other than sleep:

“She seemed very depressed and they put her on these Prozac tablets...I think she sleeps too much...because she’s depressed...it’s as though she’s just like waiting – waiting for the end...” (Alana, daughter)

(8.2) The organisational/professional level of empowerment

Chapters six and seven described how professional and organisational practices impinged on levels of empowerment. Other people’s attitudes, behaviours and service structures impacted on care received but also on the experience of dementia, and on wellbeing. For example, the lack of influence, control, communication and environmental factors described in residential settings, impacted on feelings of self-worth and self-esteem and may have contributed to increased confusion and more rapid deterioration of skills and abilities. An example is given in the text above, that is, the man who wanted to walk, but was restricted to his chair by care staff, which may have resulted in him feeling frustrated, helpless and losing mobility skills and balance more quickly than he would have done, had he been permitted or aided to walk.

It is also likely however, that the dementia affected the level of empowerment at the organisational level. For example, the low levels of communication and involvement described and observed in residential settings could have been partly a result of communication difficulty between staff and residents, as residents perhaps were not able to converse as well as they used to be able to. It may also have been more difficult for staff to involve people with dementia or promote independence, as they had lost various skills and abilities and so on. In day care settings, where people were generally in earlier stages of dementia, the levels of communication and involvement were higher.

Actions and behaviours of relatives and friends also impacted on the level of empowerment. Friends sometimes distanced themselves, as they did not understand or know a great deal about dementia and thus did not have much empathy with what individuals were going through. Their relationship with the person with dementia changed. They did not always know how to relate to that person anymore, to that seemingly completely changed person who could no longer do the things they were once able to do and communicate as well as they had been able to in the past. The stigma attached to

dementia and to mental illness generally may also have impacted on relationships of people with dementia. It has been suggested that people with dementia face a double jeopardy of being older and having a mental illness and even a triple jeopardy if cognitive impairment is included (Benbow and Reynolds, 2000). Sometimes people with dementia are depersonalised and contact with them arouses anxieties in others, which may lead to avoidance and exclusion (Kitwood, 1997, cited in Benbow and Reynolds, 2000). Family, other than immediate relatives, also distanced themselves as they sometimes found it too distressing to be around the person. One relative described how family no longer visited or phoned her mother as often as they used to, because they found the changes in her too upsetting to bear:

“The sad part is that family have left her now - aunts and cousins and such – where they would ring her up frequently, they don’t because they can’t bear it. They find it very distressing. She was so bubbly, um, she’s nothing, nothing of the person she was.” (Nicole, daughter)

The above exemplifies how other people’s behaviours sometimes impacted on and reduced the quality of life of individuals with dementia. People with dementia became increasingly isolated as the disease progressed, which was sometimes a reason for a referral to a day care centre. Attending a centre provided opportunities to meet and socialise with people.

As is discussed below, attitudes and behaviours of family and friends impacted on the experiences of people with dementia in other ways and influenced the way they coped with their illness.

(8.3) Impact of dementia on choice and self determination

With the onset and progression of the disease, people with dementia gradually lost their independence. At the level of the service user, autonomy and control deteriorated, as they were forced to accept help from external agencies or sources such as family, friends or care services or move out of their homes into residential care. Reasons for this included individuals being unable to cope with day-to-day living and/or becoming increasingly vulnerable. Joanna, a 90-year-old resident with early-stage dementia, who was prone to

falling, described slipping over on the road several times, when she was living at home and how she had started to fear for her safety:

“When I was in the house I fell three times on the road. Once there was nobody on the road - you know nobody could help me. I couldn't get up - a car came...”
(Joanna)

Joanna was one of the residents who talked about feeling relatively comfortable in the residential home that she was now in, sometimes better than she had felt in her own home. Moving to residential care may have been an empowering experience for some, as although some degree of independence was lost, quality of life and wellbeing were enhanced. Residential or nursing homes sometimes offered a safe environment and some security for people with dementia.

Many relatives also related incidents when individuals with dementia had been at risk or in danger in their own homes. Situations were described when the person with dementia had almost set the house on fire, did not eat properly, took incorrect amounts of medication, almost got run over, lost or taken advantage of by strangers. Typical comments included:

“She put a toast under the grill and she sat down and fell asleep, until the fire alarm went off. The whole house was on fire.” (Leah, friend)

“She used to get meals on wheels and half the time she wouldn't eat them. She really just couldn't cope. A couple of times she was found wandering. Luckily she met the right people, who brought her back, but she could have met the wrong people, who could have stolen all her money, so she really was beyond the stage where she could care for herself.” (Samuel, son)

Being unable to cope living alone and the person with dementia being perceived as a danger to themselves or to neglect themselves were precipitants in admission to residential care. If the person with dementia was living with a relative then usually admission to a home was precipitated by a relative being unable to cope.

People with dementia were sometimes reluctant to give up their independence and move into care and also to accept help and support on a more general basis, either at home, or in residential care. There are a number of possible explanations for this resistance to help. Firstly maintaining their independence was important to many people with dementia. Sometimes individuals had been resident in the same house for years and the thought of moving out of their homes and into a care home was very distressing, as was the thought of having to accept help with tasks that they were accustomed to carrying out themselves. Raina, a very independent woman, described her reluctance to move into a home:

“...I wouldn't want to move into one of those places...this has been my home for many, many years... I do like my independence...I've been living independently since my husband died...” (Raina)

It may have felt disempowering for people with dementia to accept help and support. Loss of control may have been experienced at the level of the service user, and with this perhaps loss of confidence and dignity at an individual level. Video data revealed several instances when residents became angry and frustrated in response to other people trying to do things for them. One man became angry and agitated when a carer tried to spoon-feed him, as he wanted to be able to do this for himself. Another resident became tearful when carers tried to escort her to the dining area; she wanted to make her own way there, in her own time.

It was also suggested that people with dementia may lack insight into their illness, not realising or wanting to admit to themselves that the situation was as bad as it was. This may be expected. Reflecting disempowering practices of other people around them and a lack of information at the service-user power level of empowerment, they were not often told of their diagnosis and given the opportunity to come to terms with and understand what was happening to them. None of the participants in the study were aware of their diagnosis. Other reasons included not wanting to be a burden to others, e.g. Hannah, a special day centre member, felt she would be imposing on her daughters lives, if she accepted a great deal of help and support from them:

“My daughters are entitled to lives of their own.” (Hannah)

It was a very sad time for those people with dementia who had to move out of their own homes, and were not able to do the things they were accustomed to doing for or by themselves. For example, Katherine also quoted in a previous chapter, talked sadly and wistfully about her past life:

“I can’t bear to talk about it...I had a lovely home, I have four sisters, but I never see them now.” (Katherine)

Quality of life was reduced for some people like Katherine. She talks about a loss of family and friends, which was discussed earlier in the chapter and was an issue for many.

Power and control were often limited further at the level of the service user, as sometimes individuals were no longer permitted to go out by themselves. It was distressing for people with dementia, who may have felt very powerless to be ‘locked in’ to their own homes as they often were, because it was felt by relatives as unsafe for them to wander out on their own, because of busy roads or the possibility they may get lost. As mentioned in chapter six, residential and nursing homes were also often locked and residents were not free to wander in and out as they pleased, again restricting levels of autonomy. Some residents talked about or indicated wanting to get out more. For instance, the video data showed one woman in a residential home to constantly wander up and down in a distressed state looking for some way out.

Well intentioned restrictions imposed by relatives were also resented. The cousin of a day centre member had locked up his cousin’s wardrobe, because he had a tendency to move everything around in his cupboard which made it difficult to find items of clothing and he spoke of the resentment this had caused:

“One thing I’ve done that he has noticed and he has been slightly resentful. He has a very large wardrobe. I have now locked the wardrobe because he would go and he would take something out and everything was in odd places and it then meant that when I was putting clothes out for him, after his bath or whatever, I had to search the wardrobe.” (Robert, cousin)

Issues such as these further limited the levels of control that people with dementia had over their lives and may have left them feeling disempowered. However, there is a dilemma here, as it may have been difficult for relatives to allow the person with dementia to do exactly as they wished. Some things were considered to be particularly unsafe or inconvenient, and arguably there are limits to the extent to which people with dementia can or cannot be empowered which may depend on individual circumstances and on the level of dementia.

(8.4) Disempowerment at a societal-inclusion level

The difficulties experienced with regard to cognitive, emotional and physical abilities; the changes in people's attitudes; and loss of control and independence resulted in reduced quality of life and opportunities for people with dementia.

(8.5) Personal coping strategies

People with dementia reacted to and coped with the changes and difficulties described in a number of ways: Personality and behaviour changes were mentioned, for example, hallucinations, restlessness, agitation, sleeplessness and hyperactiveness. Some individuals became obsessive about certain issues, for example, one resident was observed to be particularly obsessed with cutlery. When nobody was looking she would open the drawers in the dining area and remove the cutlery and take it to her room, so there were piles of knives, forks and spoons in her bedroom. A relative described her husband's obsession with cars and having a credit card:

“He's getting very obsessive about certain matters. At the moment he thinks he should have a car, obviously he hasn't got a license – he used to love driving - and he thinks he should have a credit card. It's totally obsessive now. He talks non-stop. He's asking for the card and also for the car – we have to go out and look at car show rooms.” (Nina, wife)

Behaviours such as agitation, obsessive behaviour and sleeplessness could be seen as reactions of people with dementia to their experiences or situation and their way of coping.

There could be meanings behind these behaviours, sometimes referred to as ‘problem’ or ‘challenging’ behaviours. They may not simply be symptoms of the disease, as is sometimes assumed and identifying and acting on meanings may increase the wellbeing of people with dementia and also their carers. Hoarding of cutlery or other items may in some way be compensating for the huge losses experienced. The man obsessed with cars and credit cards may have been desperately clinging to his autonomy which was gradually being taken from him. By addressing and working through these issues, ‘difficult behaviours’ may be reduced.

Additionally, sometimes the person withdrew and expressed far less interest in things than they had previously. Several participants with dementia were quite withdrawn in that they would sit huddled in their chairs for most of the day, saying and doing very little. Relatives sometimes commented on this issue:

“She’s quite a shadow of herself now actually.” (Rachel, daughter)

These experiences could again be seen as reactions of people with dementia to their particular situation. Behaviours such as withdrawal or loss of interest are often attributed to the disease process, however, they could reflect the way the person is feeling inside. For example, the person may have been very depressed because of the losses and changes they were experiencing. Another reason may have been communication difficulty. As described, people with dementia did not always feel confident about expressing themselves and for this reason may have withdrawn.

As may be expected, different people reacted and responded to their situation in different ways. Other people became more aggressive, stubborn, anxious or cross:

“She was a very lively person, who was generally always looking on the up side. She was such a lovely personality. What’s left now seems to be mostly sort of a cross, dissatisfied, anxious, unhappy person.” (Isabel, daughter)

“She got very aggressive - that frightened me, because she never was before.” (Norma, daughter)

Some relatives described more positive changes in the person with dementia, for example, the person sometimes became more relaxed or seemed happier:

“It’s made her a bit easier. She used to be very stubborn, easily irritated, um, short-tempered.” (Dinah, daughter)

“She’s changed completely since she’s had dementia. I think the Alzheimer’s has actually made her a much happier person because she was never a happy person, she is now.” (Jonathan, son)

These examples highlight the individuality among people with dementia. Dementia affects different people in different ways and people respond to the illness differently and it may be important to remember this when providing care for people with dementia.

Coping mechanisms employed by people with dementia are summarised in appendix VII. There were a number of different strategies used. These included accepting the situation for what it was and dealing with it using problem solving strategies, such as following other people’s instructions or asking other people what to do:

“ I ask. I usually ask Colin, my son. ... He’s forward – he’s good. I often ask him – you know – ‘ shall I do duh duh?’ and he says – ‘ well it’s up to you now’ – something.” (Jessica)

“She does what she’s told.” (Adam, son)

Using memory aids, for example, making lists, keeping a diary, putting up notices of things to do in prominent places, or relying on other people’s memories:

“Well, I do forget sometimes, but I make a list. Every morning I have a list by the side of my bed – to remember to do so and so when I get up, just in case I forget. My memory’s not what it was and I make a list. Oh I must do so and so – you know, it helps.” (Hannah)

“I always have someone living with me and very often I rely on their memory, you know, don’t forget to remind me, so and so.” (Ira)

I had to speak to my son. What did we do duh, duh, duh...Yes I do. That...that’s a natural thing is it? It depends I suppose. (Jessica)

Relatives also devised strategies to help the person with dementia to remember:

“She has a diary and once a week we write her diary out – everything she has to do for the week.” (Jeanette, daughter)

“I put up signs in the hall, e.g. we have a light switch – there’s a big sign...do not switch off the light because we have people living in the flat upstairs.” (Robert, cousin)

Remaining actively involved and getting on and doing things was a common approach:

“I got better as I got on with it” (Jessica).

“She likes to help, so whenever she can, she likes to clear the tables, or lay the tables – in fact even a few months ago she wanted to find a job. ‘I’ve found a cleaning job’ you know – just humour. She likes to be involved. She’s very happy if you give her something to do – even if it’s just folding napkins or something. She doesn’t like to just sit, she likes to be involved. I suppose that’s how she copes. I don’t think that anyone likes to feel that they can’t contribute in anyway. She likes to do things and I suppose that’s how she copes.” (Adam, son)

Humour was also sometimes used:

“She has a wonderful sense of humour...” (Adam, son)

Some of the coping strategies described above may have helped to empower people with dementia, by compensating for lost skills and abilities and maintaining self-esteem and levels of control.

However, sometimes people coped in quite the opposite way. They had not accepted and come to terms with the situation, but pretended that there was nothing wrong and tried to bury the problems they were experiencing. Although this was not the most healthy way of coping, it may still have served to empower individuals by allowing them to maintain some control over their situation and preserve their self-esteem. Sometimes the individual tried to cover-up their mistakes and lack of knowledge. This was apparent in some of the interviews conducted with people with dementia, as if the person did not know the answer to the question, rather than admit it, they sometimes avoided answering the question, by changing the topic of conversation, or by providing a very vague, general answer. The spouse of one resident with dementia talked about her husband 'bluffing his way' through many things, pretending that nothing was wrong:

"At the beginning he did try to cover up. He must have been bluffing his way through all sorts of things. He didn't know people, but he'd pretend he knew people and he'd embrace people he didn't even know." (Sophie, wife)

Other comments included:

"She used to try and hide it, she used to say – she'd ask me a question, I'd tell her the answer and she'd say, oh yes, of course I knew that. So in her own way she tried to cover up her problem as best she could." (Samuel, son)

"She was putting on an act. Talking naturally but talking about subjects that she knew nothing about." (David, husband)

Perhaps people with dementia were afraid of making mistakes, especially in front of others because they felt embarrassed, humiliated or were frightened of the consequences. Davis (1984) described his constant fear of making mistakes because he was afraid that with each mistake more freedom would be taken away from him:

“Certainly one of the very real fears felt by anyone with early Alzheimer’s disease is the fear of failure. I live with the imminent dread that one mistake in my daily life will mean another freedom will be taken from me. Each freedom taken places me in a smaller playpen with a tighter ritual to maintain myself.”(p.91)

Withdrawing from situations was also common. Again, people with dementia may have felt embarrassed or frustrated about the difficulties they were experiencing. They were not able to communicate in the way they had been able to previously and so stopped talking to and interacting with people altogether, which was a way of preserving self-esteem and wellbeing:

“He gave up speaking because I think he realised he wasn’t making sense...The earlier stages when he couldn’t communicate and he wanted to must have been very frustrating for him and I think this is one of the reasons why he gave up speaking, because he realised he wasn’t getting through.” (Sophie, wife)

Although, this may also have felt disempowering for the individual who was no longer able to articulate their needs and wants.

Denial was a coping mechanism used by a few people. Even when told of their diagnosis, people with dementia would not always accept that there was something wrong:

*“She would never admit to herself that there was something wrong – never.”
(Jonathan, son)*

Denial is thought to be a common feature experienced by people with dementia. Bender and Cheston (1997, p.517) describe denial as functional:

“Denial is a coping or defence mechanism that we would expect people to use when their environment is not safe enough to allow them to explore their experiences.”

They describe awareness as a response influenced by others and suggest that acknowledgement of loss and grief may enable the person to move on and to make sense of their losses. Since many people with dementia had not been informed of their diagnosis, let alone been given the opportunity to talk about their difficulties and come to terms with them, it is unsurprising that denial was among the coping mechanisms employed.

(8.6) Discussion of findings

In conclusion, people with dementia experienced a whole range of different emotions and feelings with the onset and progression of dementia. The experience of dementia was disempowering, impacting adversely on all of the levels of empowerment, affecting self esteem, skills and abilities; behaviours of and relationships with loved ones; levels of control and influence; and quality of life. Individuals reacted and responded to their experiences in different ways and employed a number of different coping mechanisms which enabled them to gain some control and self esteem. These included problem solving strategies, covering up of problems and denying any difficulties.

Findings suggest that the experiences of people with dementia, which include levels of empowerment and coping strategies may be influenced by internal but also external factors, such as the environment and reactions and actions of people around them. For example, a lack of explanation or disclosure of the diagnosis may result in self-blame, bewilderment, fear and loss of control over what is happening. Even with the best of intentions, carers who are over-protective and try to take-over may do more harm than good. The person may be left feeling angry, frustrated and self-confidence and skills may deteriorate. A lack of understanding, support and social contact may cause isolation and depression. Although there may be limits to the things that people with dementia can do, it is important to maximise opportunities for empowerment. It is also vital that people interacting with individuals with dementia have some empathy with the person and what they are going through and awareness of how their actions could positively or negatively impact on their experiences.

9 RELATIVES' EXPERIENCES OF DEMENTIA AND CARE THEY RECEIVED

This chapter explores experiences of all 28 next of kin included in this study, of their loved ones' dementia and the support and care they received. These were a group of people who also often felt they had little power and control. They endured immense psychological, social and physical pressures, which resulted in them feeling very disempowered. At an individual level, wellbeing was severely affected. Feelings of guilt, upset, fear, depression, isolation, loss, frustration and anger were experienced. In addition, loss of control over their own lives and the lives of individuals they were caring was experienced, as there was nothing they could do to prevent or help the situation and they did not always know what to expect or what would happen next. Caring impacted significantly on quality of life. Relatives were not able to engage in the same activities as they had previously; contact with friends and family members was severed and so on. Information and support were described to be inadequate and not forthcoming. Few relatives spoke of feeling empowered by receiving the care and information they needed.

On the whole, interviews with relatives went smoothly. Sometimes questions were upsetting and painful and in these instances relatives were always given the option of terminating the interview, taking a break or skipping to the next question. Sometimes relatives were unaware of the diagnosis of dementia or were in denial of it. At the beginning of the interview, next of kin were asked what they perceived their relative's problems to be and the interview was adapted accordingly. As with interviews with people with dementia, it was necessary to accept the emotional reality of relatives, while remembering that they may not always be giving a fully accurate account. This reflects the various defence mechanisms in play to protect them from what was real in the home or the true situation with regard to the person with dementia. There were a number of personal benefits for participants in this phase of the project. Interviews provided an opportunity for relatives to talk about their circumstances and feelings and articulate views about the care

received, which many did not have the opportunity and space to do on a regular basis. It is probable that individual satisfaction and wellbeing were enhanced.

(9.1) Disempowering impact of dementia on relatives

Many of the relatives interviewed referred to the huge subjective and objective pressures they experienced (see appendix VIII). These impacted on the different levels of empowerment in a number of ways:

(9.1.1) Impact of dementia on the individual level of empowerment

Initial effects of dementia

All next of kin described the onset of dementia as extremely upsetting. The experience of a relative developing dementia impacted hugely on individual wellbeing. Comments included:

“It’s very upsetting. It’s obviously a horrible thing for anyone to see their parents going through all this.” (Nathan, son)

“I’ve got to the stage now, where I think I’m almost beyond the crying. I’ve cried so much. I’ve cried an ocean I think.” (Norma, daughter)

“I think it can only be described as nightmarish. It has no rationale.” (Olivia, wife)

There was the feeling that the situation would deteriorate, never improve and feelings of loss of control and powerlessness were experienced by many relatives, who felt they had minimal influence over future events. There was little they could do to help their relative and ease their own distress and upset, which they felt there may be no end to. Norma, the daughter of one resident, described her feelings at the time her mother developed dementia:

“I was in a terrible state. I couldn’t see the light at the end of the tunnel. It was awful you know, really awful. I lost about two stone in weight.” (Norma, daughter)

Nicole described how difficult it was to cope with the unpredictability of the illness. She felt it would be somewhat easier to deal with if she knew what would happen or what to expect, so that she could prepare herself:

“You don’t know what’s going to happen. You don’t know how it’s going to affect her. I’d like to know what’s going to happen and I don’t know whether that makes it easier or worse but at least you can prepare yourself.” (Nicole, daughter)

Next of kin described their distress as their relative’s condition declined and abilities and skills were lost, for example, the spouse of one resident described how painful the deterioration was for her to watch:

“It’s awful, a terrible situation. Each phase is a terrible phase. You sort of have a plateau going along and then something else stops and it’s a big hurdle you have to get over. Then you go along on another plateau...You get used to this plane and it’s just dreadful when you realise he’s not going to stay like that. There’s going to be something worse. I mean he’s just reached another stage now, which has hit me very badly. He used to walk around a lot, but he’s not walking around anymore, he’s not swallowing his liquids terribly well anymore and I realise that’s he’s at a more advanced stage and it hurts terribly.” (Sophie, wife)

Other relatives described similar feelings:

“I always find it very distressing to see her slowly going downhill.” (Samuel, son)

Feelings of guilt and shame were sometimes experienced at not recognising early symptoms. The son of a resident described how his mother had started to forget major issues, but he had not recognised, or perhaps not wanted to acknowledge that there was a problem:

“She would sometimes ask me simple questions that I’m afraid - I’m ashamed to say, I didn’t realise at the time were sort of part of the problem. Simple things. She

would say where are the lights? I remember one day and I was rather taken back by that, um, she knew that something was wrong, but didn't know what. I tried to reassure her. To be perfectly honest with you, it just didn't occur to me that it was Alzheimer's. I thought that it was just growing old, um, so I was probably the last one to really know what it was." (Samuel, son)

Other relatives also felt ashamed:

"I'm just flabbergasted that I never realised." (Joel, son)

Sometimes difficulties such as memory loss were attributed to old age and thought to be nothing out of the ordinary. Although it is possible that next of kin sometimes did realise something was wrong, but did not want to acknowledge or confront the problem, as the consequences may have been too awful and distressing to cope with. It was perhaps easier to pretend that any changes in the person were normal. Unawareness of early symptoms and the diagnosis prevented people with dementia and their next of kin seeking or benefiting from help and support early on, which may have been very valuable to them. It may have been empowering to understand what was happening and how the situation could be helped or managed. Individuals would have been in a better position to make choices and decisions about future healthcare. Awareness may also have enabled individuals to develop proactive coping strategies at an early stage. Sometimes help was not sought until such time as the situation became much worse and relatives could not cope any longer or deny that there were problems.

Relatives, who were not aware of what was happening, sometimes blamed themselves or the person with dementia for the difficulties experienced. Lack of awareness sometimes resulted in behaviours which may have exacerbated the dementia and impacted negatively on wellbeing of both the person with dementia and their relative. The wife of a resident described how frustrated and angry she had felt at her husband. She had believed that difficulties were a result of marital problems:

"I just feel very bad that I didn't realise before. I feel upset at the times I used to shout at him and say can't you remember, why don't you pay attention or haven't

you got any interest in what the children are doing that sort of thing. But it was very hard. It was very difficult...I thought maybe our marriage wasn't working particularly well or something like that - although we didn't quarrel. There were things that I found very frustrating and I got very depressed at the time....Now looking back, I realise what it was all about." (Sophie, wife)

She did not at any time suspect that her husband had developed dementia, as he was too young and like many people she believed dementia to be an illness which affects older and not younger people. She felt very guilty about the way that she had treated him. Other relatives also felt guilty for blaming the person dementia at the time they did not fully understand the situation. When reflecting back, they also wondered whether there was any action they could have taken to help or prevent the situation,

"You often think to yourself, was there something that you could have done to stop it all happening, but there isn't – there really isn't." (Nicole, daughter)

Changes in the person with dementia and impact on relationships with relatives

Relatives often referred to the person before the onset of dementia. They were devastated by the changes in the person. One daughter described her mother as a very intelligent woman, who had had her own dress making business. She found it very painful to watch her condition slowly deteriorate:

"When you see someone who drove a car up to a few years ago, who did private dress making, made dresses and ball gowns and did the crossword. Did the puzzle games, watched the tele, answered any of the questions in any of the quiz games deteriorate so quickly, it really is horrific." (Emma, daughter)

Other relatives also described their distress, for example, the wife of a resident, Olivia:

"This was a man who was a champion bridge player, a most wonderful driver, a business man, a man who could do the Times crossword in three quarters of an hour. He was extremely clever mathematically - all that was there – all that was

potentially given is gone – it’s devastation. I mean to be glad that a man like that with such a good brain can – you’re only too pleased that he recognises you – how can you feel? Ghastly, terrible. There aren’t the words are there? It’s a terrible thing.” (Olivia, wife)

Changes in the person with dementia inevitably resulted in a deterioration in relationships between people with dementia and their relatives, which was again upsetting and a situation that relatives felt they had very little influence over.

“It’s terrible really, I don’t feel I have a relationship with him.” (Aaron, son)

Individuals with dementia gradually became unrecognisable. The person could no longer communicate in the way they had been able to and do the things they had previously done. Their personality had changed and the loving affectionate person, the friend with whom they shared activities, thoughts and feelings had been lost. Relatives no longer felt able to relate to the person with dementia in the way they had previously been able to. Comments of relatives included:

“This pain at not knowing this woman that was once a most vibrant amazing mother, a fantastic woman, absolutely fantastic. I don’t think she knows my brother, I think she recollects me, my brother she doesn’t, which I find very tragic. He finds that very difficult.” (Emma, daughter)

“Your best friend is your mother. You can always go out shopping and talk. If you have any problems, you always go to your parents about it and unfortunately you’ve lost all that. I mean when I go and visit her now, she’s just a shell really, she’s not my mum, not as I know her.” (Norma, daughter)

In keeping with these findings, informal carers in Clarke and Watson’s study (1991) described the loss of mutuality and reciprocity in their relationships with people with dementia. Wuest et al (1994) describe how people with dementia and their informal carers gradually “become strangers.” In Moore’s study (1997) which explored the experiences of family caregivers of people with dementia, relatives described the person with dementia as

'someone I once knew,' and Orna's study (1990) revealed that relatives lost parts of their own identities, as people with dementia were no longer able to participate in relationships.

Sometimes the person with dementia no longer recognised their relative and that was very hurtful. The son of a resident described how painful this was for him. He had been an only son and had previously felt very loved by his mother and that had now changed:

"I don't think she really comprehends in any real clear way who I am. She probably recognises me as a face from the past, but I'm not sure that she realises I am her son...That makes me feel very sad. When I think back to the person that she was and the enormous energy that she had and her love for me. I'm not saying that she doesn't love me, but all the demonstration of that and all the verbalisation of that has disappeared. I like to think that she does from time to time recognise me, but I couldn't substantiate that in any way." (Samuel, son)

Other comments included:

"I don't believe he knows who I am any more, whereas two years ago he would have known." (Josh, cousin)

"It's the same response when a stranger comes in as when a member of the family comes in." (Norma, daughter)

Although the person with dementia did not always know the relationship, sometimes some recognition or bond remained, which that person usually expressed non-verbally. They became emotional or seemed very happy during the period their relative was visiting. For example, the husband of a resident described how although his wife did not know her relationship to her daughter, she recognised her as somebody that she knew and loved:

"My daughter comes every three weeks, she doesn't know the relationship but there's a bond somehow, there's a definite bond. She likes seeing my daughter, while she's there she's very happy. Doesn't know who she is. I'm sure she doesn't know who she is, but there's a very strong bond." (David, husband)

The relative of another resident did not think his cousin knew exactly who he was, but felt there was some recognition, as when he visited he became emotional:

“When I came - when the nurse said you’ve got a visitor, he responds with his eyes closed and she said open up your eyes, see who it is. He resists for a little bit and then he agrees to open one eye and she said oh it’s John and the eyes well up.”
(Josh, cousin)

This was applicable to people right up until the advanced stages of dementia.

Communication difficulties, effects and coping strategies

Communication difficulty was an important issue which also impacted adversely on individual wellbeing and on relationships. Perceived inability to relate to or communicate with the person with dementia was often a source of distress and frustration. The daughter of one resident described her huge loss, as her mother could no longer communicate that she loved her and vice versa and that was very painful to deal with:

“I was denied the ways to show her that I loved her and she is not able to show me her love for me, so that has been sort of painful.” (Isabel, daughter)

The husband of a resident described how hurt he felt when he was not able to give his wife what she was requesting, because he could not understand what she was saying:

“Sometimes she’s trying to tell me - she’s asking something of me and I don’t know what she wants. I don’t understand her. It’s all gibberish coming out - that’s what hurts, you see and also, sometimes when she’s asking something of me and I can’t give her that, that really hurts.” (David, husband)

These comments have resonance with another spouse who described the pain at not being able to give her husband what he wanted, but having to give him what *she* thought he

wanted. Extreme helplessness was experienced by relatives who did not know what to do and how to respond or help:

“It might be a matter of him not being able to communicate, not being able to say he wanted to go to the toilet or something like that. That was one of the worse phases when he first became incontinent. Not being able to say what he wanted or when I had to feed him because he couldn’t and I just had to give him what I felt he wanted not what he wanted, because he couldn’t tell me.” (Sophie, wife)

Other relatives found communication difficulties to be very frustrating and annoying. The son of a special day centre member described how annoyed he felt when he could not understand what his father was saying or what he wanted. Nothing he did seemed to please him:

“Sometimes he’s very annoying and sometimes I’m shouting at him. He’ll come in and he’ll sort of say come over and he’ll point at the television and the television will be on and you’ll say ‘do you want it off?’ And you can’t make out whether he’s saying yes or no, so you turn it off and ‘is that okay?’ And he’ll say ‘no.’ You don’t really know what he wants.” (Aaron, son)

This may not only have been frustrating for Aaron, but may have felt very disempowering for his father who could not communicate his wishes anymore.

Relatives often found they had to constantly repeat themselves in conversation because their relative had no recall of what they had just said, which was sometimes a source of extreme distress. Comments included:

“It’s very difficult because I’ve got this problem of trying to remember that she’s not trying to wind me up shall we say by not remembering things. It’s nerve shattering. She asks me a question and then after I’ve answered she asks me the same question and I do find that very, very hard and I get very frustrated.” (Benjamin, son)

Next of kin tried to remember that behaviours such as these were part of the illness and the person was not intentionally being difficult or annoying, but it was not always easy. When difficulties first started, relatives did not always understand why the person with dementia was behaving in these ways, such as asking the same question repeatedly, and they blamed them for it and became angry at them. Feelings of disempowerment may have been experienced by relatives, who did not always have the information they needed to understand and deal with the situation. They felt there was little they could do to help or influence their circumstances. They had to tolerate things as they were.

Some relatives had developed ways to overcome these communication difficulties to some extent. These may have been empowering, affording relatives greater control over the situation. The strategies employed may also have helped to empower people with dementia, by assisting them to communicate their views:

Communication was said to be enhanced in one to one interactions, as people with dementia found it increasingly difficult to cope in groups of people:

“I think he could understand some of it on a one to one, it’s obviously always more difficult when there’s a lot of people.” (Aaron, son)

Other strategies relatives employed included altering their speech when talking to the person with dementia, which sometimes facilitated communication. Relatives described using simpler language and speaking more slowly, strategies which were useful when conducting interviews with people with dementia. In addition some found it useful to talk in a way that did not need an answer, in a more authoritarian way, more directly, or role play, perhaps if their relative thought they were someone else. Comments included:

“I speak more slowly. This is something I’ve realised over the years, when he first started going to the day centre, he was happy because the pace was the pace he could understand. He wasn’t lost with people rushing backwards and forwards and moving quickly and the fact that things were done slowly – things were given to him slowly, he wasn’t moved quickly. I think that helped and I started to do that as well

and my children as well did the same thing – did things much slower.” (Sophie, wife)

“I decided there was no point in telling her that her mum and dad were dead or that her husband was dead or that her brother died in Australia years ago. You’re my brother John – okay I’m your brother John and I will talk to her as her brother John. You know certainly she remembered Dad, so I would talk to her as Dad.” (Nathan, son)

“You end up being quite authoritarian with her in a way. That is, it’s like this and so on and maybe I do talk to her a bit more – not as a child, I wouldn’t say that, but I’m sort of much more direct with her than I would have been when I was younger.” (Anna, daughter)

It was also helpful to attend to or use non-verbal language. As may be expected, this was particularly important where verbal communication was difficult, for example touch:

“What we’ve done, the family, we continually tell him how much we love him. We touch him – there’s a lot of touching, because I think that’s a very important method of communication. Stroking his hands. There’s a lot of touch in our family. A stroke of the nose or a stroke of the face – just fun.” (Sophie, wife)

The son of one resident talked about the usefulness of observing his mother’s facial expression, to understand how she was feeling. This reflects work of Jansson et al (1993), who observed facial expressions of people with advanced dementia and found it was possible for them to communicate their experiences to others. The analysis of the video-taped interviews in this study also revealed observation of facial expressions and other bodily gestures to be helpful when seeking to understand and make sense of what individuals with dementia were saying and how they were feeling.

“She communicates by facial expression. She smiles – she smiles very easily. She can recognise a face and she communicates her happiness by smiling and laughing and showing pleasure.” (Joel, son)

Miming or sticking up signs to remind individuals with dementia of certain issues or perhaps writing things down in a diary were also sometimes useful:

“Signing helped initially. For instance would you like a cup of tea? So like that – miming.” (Nina, wife)

Sharing an activity was sometimes an effective means of interaction. For one daughter, offering her mother chocolate cake was a way of communicating with her:

“All I can do now is try and offer her food, which is funny. It’s the only like – the bit of communication we have is I bring her a little chocolate cake and she was quite enjoying those chocolate cakes that I was bringing her.” (Rachel, daughter)

Going for walks or looking through photographs were also useful:

“During the summer I said ‘do you want to go out for a walk, it’s nice to go out for a walk around’...he’d shuffle about or ‘lets go to your room,’ because I brought him some picture frames. I wanted him to select photos from his collection, that I wanted to frame, which I thought might be therapeutic...” (Josh, cousin)

In addition, video recordings sometimes revealed relatives just sitting quietly with the person with dementia, holding their hand. Others shared a meal with their relative or looked through magazines with them. Employing these non-verbal methods of communication may have helped relatives to feel empowered, in the sense that they were now more able to relate to their relative as they wished to. In addition, they often provided comfort to those relatives, who did not feel able to communicate with or relate to the person with dementia in any other way.

For others, particularly those with relatives with more advanced dementia, non-verbal communication was not very useful. The daughter of a resident described her mother as having no non-verbal communication at all now and not knowing how she was feeling:

“There isn’t anything really, nothing that I could understand. It’s all – she’s just the same every time you go out...if she does sort of smile, I don’t think that she realises that it is a smile or anything like that, oh no, not at all, no...She hasn’t got much body language because she’s in a wheelchair.” (Norma, daughter)

Sometimes touch was not very useful either. One relative said he did not think his mother was always aware that he was touching her:

“I mean you can hold her hand for a minute – for a couple of seconds and touch her, but today I had a feeling she wasn’t aware who was touching her. That’s how bad things have become.” (Samuel, son)

Other relatives described themselves or individuals with dementia as not being particularly tactile, thus touch was not often used to communicate:

“Not particularly. Only to wake him up. I don’t think he’s a particularly tactile person and I’m not particularly.” (Josh, cousin)

It was very distressing for these relatives who felt they were no longer able to communicate with or relate to the person with dementia in any way, as they felt the person with dementia had been completely lost to them.

Losses experienced and impact of these

The losses experienced were immense. Akin to the issues mentioned above, relatives felt they had very little influence over these and they impacted significantly on individual wellbeing, sometimes resulting in feelings of isolation and depression. Emma, the daughter of one resident who was extremely close to her mother, described how she had lost not only her mother, but her best friend:

“I’ve lost something haven’t I? I have lost a very special bond, a special relationship. You don’t realise until you’ve lost it, how much it meant to you. We

were always close, but she was my best friend and I've lost my best friend and I'm grieving for what I've lost." (Emma, daughter)

Emma felt unable to relate to her mother anymore, and they could no longer do and share the things they had previously with each other and at times it was very sad and lonely for Emma. Intense loneliness was a common feature experienced by relatives, especially spouses when their husband or wife moved into care which was sometimes a very traumatic time for them. This may be expected as spouses were often accustomed to being with the person with dementia day in and day out, especially if they were caring on a full-time basis and that person had been their constant companion. In addition, often family and friends had become distant or were lost, which accentuated feelings of loneliness. Sophie, the wife of a resident described how lonely and isolated she felt without her husband. She had also lost touch with many of her friends who did not understand what she was going through:

"At the moment I'm going through a very difficult stage. I'm missing him dreadfully at home. I'm very lonely...A lot of people said oh it must be much better for you now he's in a home – but it's not it's worse. Yes, my time is more my own. I can go to the shops or to the cinema. I don't have to get someone to come and stay with him. It's desolate without him – he's here, but he's not here. It's very tough and I'm not feeling very happy at the moment. I'm going through a rather depressed stage." (Sophie, wife)

It is sometimes assumed that once the person with dementia moves into a care home, life becomes much easier for their relatives, however comments such as the above suggest that although the physical pressures may be reduced, psychological distress continues. These findings reflect work of Orna (1990) and Monahan (1995), who found that despite the physical separation, psychological and emotional links remained. Sophie felt very depressed without her husband:

"I'm not happy and I've been on anti-depressants for years. Prozac keeps me going." (Sophie, wife)

Other relatives also described feeling depressed, particularly spouses of people with dementia or those co-residing. These results reflect findings from studies such as those of Clair et al (1995) and Cuijpers (2005) which suggest that depressive symptoms and disorder are commonly experienced by carers of people with dementia.

(9.1.2) Empowerment at a societal inclusion level

The feelings of loss of control, influence and wellbeing described all impacted on quality of life, a component of the societal-inclusion level. However, quality of life was affected in many other ways, some of which are discussed below. Some of the issues explored below also affected individual wellbeing. Because the levels of empowerment are so very closely interrelated and interlinked and the different issues are complex, it is not always possible to assign each issue to a particular level of empowerment. Some issues may be influenced by and impact on more than one level.

Effects on social interactions and relationships with others

In addition to gradually losing a spouse or other relative with dementia, relationships with friends were sometimes strained, which was especially applicable to those caring full time. Looking after someone with dementia impacted on quality of life, as relatives sometimes found themselves denied the social opportunities and interactions they had enjoyed before. There are a number of reasons for this. Often, there was a lack of time to socialise with others. Relatives felt too exhausted and they did not always feel very relaxed going out with their relative as they did not know how they would behave. The daughter of a resident described her mother's aggressive behaviour in restaurants and in other public places:

“We would take her into restaurants. Her behaviour was very aggressive – plates going across the table...we couldn't really take her out anywhere because she was aggressive – not physically, but just verbally.” (Norma, daughter)

Another relative described his father's inappropriate behaviour and was reluctant to take him out for this reason:

“We would be out with him somewhere and he would always be going up to other people and talking to them and it would be very irritating and going up to children - inappropriate behaviour.” (Aaron, son)

It was often embarrassing and awkward to go out with the person if they behaved inappropriately or aggressively. Others did not always understand why they were acting as they were and it was not always easy for relatives to explain. Similarly, friends did not always understand the behaviours of the person with dementia, they sometimes felt awkward and anxious and distanced themselves from the person with dementia and their family, further increasing isolation. Sometimes, family relationships were also strained, especially when much of one family member’s time was spent caring which left them little time to spend with others in their family. When they had free time they felt too exhausted to be able to devote much attention to their children or spouse:

“It’s a big strain on your relationship with your husband as well.” (Alana, daughter)

Looking after a family, maintaining a social life, caring for somebody with dementia and in some cases working as well was extremely difficult.

Physical and social pressures

In most instances, a relative developing dementia had a marked affect on the lives of family members. Relatives sometimes had to forfeit their usual activities to care for their relative with dementia, such as time they would normally have spent with their family at home:

“I suppose it's affected my, uh, way of life. I'm here every Sunday, instead of perhaps going out with family.” (Samuel, son)

Quality of life was reduced, as caring obligations meant that relatives were not always able to engage in the activities they wanted to. In addition, and at an individual level, caring sometimes resulted in a considerable amount of stress, strain and even bitterness. Individuals were occasionally a little resentful of the time they had to give up to care for the

person with dementia. For instance one daughter, Anna, described herself as always having had very little free time, as she worked full-time and had spent many years bringing up her son. Her son was now older and therefore did not require as much attention, however she found herself spending her new found free time caring for her mother:

“It means, at a point in my life, where I was just beginning to get a bit of time for myself, because my son is now nearly 14, um, I have no time for myself. It’s very, very time consuming. Almost impossible to drop in for a few minutes, um, things happen and then there’s also this house to keep turning over, so something happens with the plumbing and there’s a flood. I cannot believe how much work one lady generates. I do not know what people do if they’ve got two parents to look after or there’s only one of them. It’s just incredibly time consuming.” (Anna, daughter)

Other relatives also referred to the excessive time spent caring and the stress this induced. They found themselves having to provide increasing levels of support as the illness progressed and the person with dementia was able to do less for themselves:

“It’s very demanding and very time consuming and it’s very stressful.” (Deborah, daughter)

“Most days I have to do everything myself, including the washing, shopping and collecting pensions. And I’m on call 24 hours a day in case of accidents.” (Michelle, daughter)

Michelle who is quoted above lived separately to her mother, however she found herself carrying out all of her mother’s chores on top of her own. Some relatives, daughters of individuals with dementia particularly, shopped, cleaned, washed etc for their own families and then did the same again for their parent and sometimes it was too much and reached a point where they were unable to cope. Another relative commented:

“I used to do all her shopping, all her laundry. It got to a point where I just couldn’t cope anymore.” (Emma, daughter)

It was especially stressful for those who also had children to look after, as they had the responsibility of caring for them *and* a parent. One son described the immense pressure and strain he was under supporting his mother who would call him countless times a day. He felt she needed more attention than his children:

“I don’t get as much need to worry about my children and they’re 14 and 18 as I do with her, because you know, every time the phone rings it’s going to be her, asking me ‘what do I do now?’ I’ve had to sort of take away from her my office number because I was spending more time on the phone to her, than I was being able to do work.” (Daniel, son)

As discussed in a previous chapter, people with dementia sometimes felt very confused, frightened and bewildered; they were in need of constant reassurance and were very dependent on their relatives for this. However, it was not always easy for relatives to cope with this responsibility, especially when many of them had multiple commitments.

As would be expected, those who were co-residing (usually spouses) were also particularly affected by the stresses of caring. One spouse described how much her life changed when her husband developed dementia. She gave up her work and interests to care for her him:

“I haven’t had to work. My husband has always supported me. I have done a lot of voluntary work and I had to give it all up, because I realised that my time now was to be devoted to my husband. Then I went to help him at work, because I could see things were not going well at all.” (Sophie, wife)

She described how her husband’s business had to be liquidated because it had declined, as he had been unable to manage it properly since he had developed dementia and how terrible it had been for her. She suddenly found herself having to take on the responsibility and support him, having depended on him for years.

“I felt very shocked, having been leaning on him, I suddenly had to take on all the responsibility myself and I gradually found over the years that I was having to support him more. I’m not talking about financially. I’m talking about mentally

having to support him, having to remind him about things, where as I had been dependent upon him all the time. I had to start doing things for myself. And then it gradually got worse and worse as the illness deteriorated.”(Sophie, wife)

Other relatives also described changes in their lives, as a result of the huge responsibilities and pressures of caring. For instance, they were not always able to go away on holiday. They felt constantly worried about the person’s welfare wherever they were – they could never relax:

“My husband and myself haven’t had a proper holiday for years because of this problem, and even now, I don’t really go away abroad, because as I said, being an only child, if anything happened to her.” (Norma, daughter)

“It’s just changed my life completely. There are so many things that you can’t do. It just changes your whole life.”(Caleb, husband)

“If I’m enjoying myself, I wonder what she’s doing. I don’t know why I’ve allowed it to take over my life. Perhaps it’s that I feel like I’m looking after a child – that responsibility.” (Nicole, daughter)

Many relatives, especially those that co-resided with the person with dementia, mostly spouses, described how stressful the situation was at home and how caring was a 24 hour job:

“It was stressful because it involved being up 24 hours a day, seven days a week and it got to a point where I couldn’t do that as one person. I didn’t have anybody living in to help me.” (Olivia, wife)

They described their relatives’ constant demands for attention. The daughter of one resident described the situation when her mother was living at home with her. Her mother wanted her total attention and became angry when she spoke to or interacted with anyone else:

“She would want to be like the queen – you shouldn’t talk to and look at anybody else.” (Norma, daughter)

Similarly, another daughter described her mother’s dependence on her:

“My husband and I looked after her for a week while my sister went away. We went and stayed with her. She would come into our bedroom and wake us up in the middle of the night. And another thing she was doing was phoning day and night, non-stop, me and my sister, all through the night. I came down and there was something like 17 messages. We used to get up in the middle of the night and go down there and see you know what was wrong and there was nothing wrong... She wouldn’t let me out of her sight and it was just very, very difficult and night time was awful. She had hallucinations. She had bad dreams all night long. She would call me all night long, so we couldn’t sleep.” (Rachel, daughter)

Again, people with dementia may have felt very confused and frightened and were very dependent on their relatives for emotional and practical support. In addition, relatives were required to be constantly alert of potentially dangerous situations, as if they left their relative even for a short period of time, that person may have unintentionally injured themselves or caused damage to other people or objects around them. Comments included:

“They can hurt themselves, so you’re ever aware – you have to be. I mean I always kept this balcony door locked and took away the key, so he couldn’t get out in case he would go over the top.” (Olivia, wife)

“There are times when he’s left the gas on, the hob on, left the iron on, so that’s why I never leave him.” (Sarah, wife)

There were many sleepless nights with constant demands for attention and worrying for the safety of the individual with dementia. The husband of one resident described the situation when his wife had still been at home, and talked of how exhausting and difficult caring had been for him:

“It’s a labour of love – put it that way. It was very, very hard. Most nights she was awake. I kept a chair against the door so she couldn’t get out.” (David, husband)

There were many, many additional stresses of caring, such as issues relating to incontinence. Some relatives found themselves constantly ‘cleaning up’ after the person with dementia which was stressful and time consuming:

“He has had accidents with faeces, um, I mean that is the worst thing. That is the worst thing for my sister, if he goes there and he has that sort of accident.” (Aaron, son)

Embarrassment was sometimes experienced if the individual with dementia had ‘an accident’ at someone else’s house. A wife of a community day care centre member described how awkward it was for them to visit other people for this reason:

“We were invited around to some friends for dinner the other night. I don’t normally like taking him because I’m worried about – if he sits on someone’s chair and makes it wet.” (Sarah, wife)

(9.1.3) Reactions and coping strategies adopted

Different relatives found different aspects of caring more or less stressful than others. Some had more difficulty coping with incontinence issues, some with ‘difficult’ behaviours, some with repetitive questioning, others with communication issues and dealing with demands for attention. Zarit et al (1986) also identified that carers react and respond to situations very differently and suggest that being aware of this may be important when planning interventions to reduce stress levels. Levels of stress experienced varied, depending on different factors, such as the severity of the dementia, the length of time caring, the coping mechanisms employed, the level of support received, whether relatives were caring full time, whether they were co-residing and personal characteristics. Spouses were more likely to take on a full time caring role and were therefore under significantly more stress than children of people with dementia. Sons and daughters of people with

dementia were less prepared or less able than spouses to care full-time, as often they had full time jobs, families of their own which were under a great deal of pressure and had been living independently to the person with dementia before the illness. Spouses were co-residing, they did not have young children to care for, they were more likely to be retired and were therefore able to provide more support for the person with dementia during the day. Often if the person with dementia moved in with their daughter or son, this was a temporary arrangement and it was not long before they were admitted into a care home or moved to sheltered accommodation. The daughter of a day centre member described how difficult it had been living with her mother:

“I couldn’t really have coped with it permanently. I was beginning to feel totally claustrophobic by it all, so it would not have worked out, because I would have started resenting her - I know.” (Alana, daughter)

She felt sheltered accommodation would be more suitable for her mother and provide more support, as she and her husband both went out to work during the day. This accommodation provided many opportunities to participate in activities and outings and she felt her mother would benefit from increased social stimulation and opportunities to meet and mix with other residents in the block, which would enhance her quality of life.

“We thought it would be a good idea for her – a flat in a warden – in a retirement block...they used to have so many outings and things, which she used to go on, and they played cards 3 or 4 nights a week, they had bingo one night.” (Alana, daughter)

Relatives, particularly spouses, described increasing stress levels and the intense exhaustion felt towards the approach of residential care. Comments included:

“I think I was in a worse state than he was. Physically I certainly was. I mean the exhaustion that I felt – even his doctor said to me, ‘You’re at the end of your tether aren’t you?’ And the answer was ‘yes’ – I was.” (Olivia, wife)

“My sister - we could all see that she was struggling under the strain of it all. She wasn't her normal self. She was like – she was at the end of her tether. In the end I managed to persuade her to put her in a home. I was telling my sister, no you can't cope. We couldn't cope, there was no way. She had to go somewhere.” (Rachel, daughter)

Admission into residential care

Next of kin being unable to cope with caring and fears for safety were reasons for people with dementia being admitted into care. The enormous stresses and strains of caring were described above and at the time the person moved to a home, relatives were often no longer able to cope. It is probable that relatives experienced feelings of loss of control over their situation, as at that point they were no longer able to maintain their own wellbeing and/or care for the person with dementia. Kellet (1999), in a study exploring carers' experiences of nursing home placement, also found that placement of a relative in a home was a final desperate step, after previous efforts to maintain a relative at home had broken down. In addition, several relatives related their growing fears which included their relative perhaps leaving the house at night and coming to some harm or getting lost or them falling or hurting themselves in some way. Olivia, the wife of one resident, described her concerns when her husband was living at home:

“There were many incidents. It was quite horrendous, I think, and it began to make me ill – the strain and not being able to sleep, because I was always worried – what would he do? I've got no locks. I couldn't lock him in. I had to lock the front door, because he used to go and wander.” (Olivia, wife)

The son of a resident who was co-residing with his mother commented:

“It was not only a 24 hour job, it was a major worry that she would fall because we're on two stories, downstairs and upstairs and that she'd do something dangerous in the sink or in the kitchen, or that she'd turn the oven on, so you know we had to watch her the whole time.” (Joel, son)

It was a particularly anxious time if next of kin did not live with the person with dementia, as they were constantly worried for their safety:

“One day we didn’t get any calls at all and my husband and I went round there. We were very worried, and we didn’t have her keys, but her carer, the lady who helped had the keys and when we went round to go there we found her lying on the floor upstairs. She hadn’t been able to move that’s why she hadn’t phoned.”
(Rachel, daughter)

Relatives, particularly those who did not co-reside, sometimes felt frightened and helpless. They felt they had little influence over their relatives’ welfare and what was happening to them which sometimes resulted in them placing the person in residential care or what they perceived to be a place of safety.

There were however a number of factors which delayed or influenced placement of a person in a home. Sometimes there were no vacancies:

“I thought about residential care earlier, but I couldn’t get him in.” (Sophie, wife)

“There’s not sufficient places in the homes, I mean we waited six months for her to get into Jewish Care.” (Norma, daughter)

Delays also occurred if relatives felt guilty. They sometimes felt as if they were somehow washing their hands of the person and the responsibility that went with them, by putting them into care. Because of this the person with dementia sometimes did not move to a home until the situation had reached crisis point. The son of one resident described how guilty he had felt:

“We had a couple of years of hell because I couldn’t accept the idea that she should move into a home. I just couldn’t. The idea of sending my own mother into a home - that was horrific, I felt so guilty and so awful...I was persuaded by the carer that she, for her own sake would be better off in a home. To me that sounded like neglect on our part and I could never imagine when I was younger, actually sending my

parents to a home. That's it – when you want to get rid of – when you don't care about your parents anymore. That was awful. So I wouldn't let her go. That went on for a long time because they wanted her to go into a home much earlier and they were right, I was wrong and I was doing it for my benefit, not for hers. I was holding her back because I felt guilty and it was the wrong thing to do – bad mistake. I couldn't bear the idea of her going into a home, but when she got into the home she was actually happier.” (Joel, son)

Cultural factors may have contributed to the level of guilt experienced. As discussed in chapter two, Jewish families have traditionally been very close and the responsibility of caring usually lies within the family, not outside. This may be partly because of past discrimination against Jewish people who were not always welcomed by statutory services and had to develop their own systems of care. In addition, older people have always held a central position in the Jewish family and it has been thought of as the responsibility of the younger generation to care for their parents, if they become unwell. Thus, perhaps Jewish relatives in this study felt more guilty about placing their relative in a home than somebody from another culture would have. One daughter Emma described experiencing ‘Jewish daughter guilt.’

“I have what they call Jewish daughter guilt. It's something I find very, very difficult.” (Emma, daughter)

Placing a relative in care was sometimes a very traumatic experience for next of kin. Loss of the role of carer was sometimes experienced and with that not feeling needed anymore. This was Isabel's experience, the daughter of one resident, who had cared for her mother for a number of years, as she had also experienced difficulties when she was younger. When her mother moved to a home she felt a little useless as she did not know what her purpose or role in life was anymore and this was difficult for her to deal with:

“I found my mother going into a home much more traumatic for me than I had anticipated it would be. I had always taken care of her and when she went into the home, I really had to come to terms with the fact that I wasn't needed in that role anymore because the carers were taking care of her. I went through a period where

I couldn't actually figure out what I was for – being a daughter, if I wasn't taking care of her and I found all that actually quite painful.” (Isabel, daughter)

This finding supports a study by Hagen (2001) which explored factors affecting caregivers' decisions to place family members with dementia in a home. It found that the extent to which carers saw themselves as having meaning and purpose in their lives other than caregiving influenced the ability to make a placement.

In addition, a few relatives had negative perceptions of residential homes. They thought that residents were drugged, not washed properly and thought that homes were places people went to die rather than to live. Aaron, the son of a special day centre member, who was finding it increasingly difficult to cope at home caring for his father and his baby son commented:

“I wouldn't want to put him in a home, rather if necessary have someone to come and live here. They drug the people. The old person might say they don't want to be washed and they don't have to be washed.” (Aaron, son)

Michelle, the daughter of another day centre member, commented:

“As far as I see, you go in a home to die and there is no way I'd consider that until a) mum didn't know us and secondly the carers couldn't cope.” (Michelle, daughter)

Other factors which influenced the decision to place someone in a home included the levels of informal and formal support received which are discussed later in the chapter. These impacted on the ability of relatives to cope with the stresses and strains of caring.

Coping strategies

Relatives employed a number of different coping strategies which helped them to continue to care for the person with dementia and maintain their own wellbeing. These were

empowering in the sense that they increased the levels of influence relatives had over their circumstances. They included accepting the situation and the problems for what they were:

“I just accept the situation. I just feel that each time I visit him, I should accept a deterioration.” (Josh, cousin)

Benjamin, the son of one resident, described how he had eventually come to terms with and accepted the situation. Initially it was very difficult and distressing for him as he did not understand why his mother was behaving as she was and she seemed so different:

“When it first started to happen, it upset me to the extent where I got annoyed with her. I began to realise after a period of time that there’s no point getting annoyed because she can’t remember something I’ve just told her, so I’ve eased into it, and I accepted it and I don’t rebuke her because she’s just been told the answer to something. But at first I did, because it was I suppose my way of expressing how upset I was that it was happening.” (Benjamin, son)

Some relatives described just getting on with things and taking each day as it came. Comments included:

“I’ve coped the only way I know how - that’s just to get on with life. Uh, I occasionally talk to people about it, but not very often. Everybody has their own problems, nobody wants to hear anybody else’s. So I just get on with it and get on with life, with always having this sort of in the background.” (Samuel, son)

“I do cope. You have to cope. I just take each day as it comes.” (Anna, daughter)

“Best you can – you have to carry on and um you have to cope – just do the best you can.” (Nina, wife)

Sometimes this was extremely difficult for relatives, because there seemed to be no immediate end to their suffering. They felt powerless, in the sense they did not know what to do or how to help the individual:

“Cry. Uh, because there is nothing else – it’s life, it’s not as though you can do anything about it. You’ve just got to watch it and accept it and suffer with it.”
(Nathan, son)

“You have to, but it’s getting difficult now – very difficult, because it’s sort of endless. You don’t get a break obviously.” (Caleb, husband)

Sometimes relatives found it helpful to seek some support - informal support from friends and relatives or more formal support such as counselling. Access to this enhanced the ability to cope:

“I didn’t cope with it – I had to have counselling, um, because when I was at work I used to scream at people at work and I thought this is out of character, why am I like this all the time? I’d cry a lot...” (Nicole, daughter)

Other relatives avoided the situation or shut it out, for example, the son of a resident described trying to distance himself by not visiting his mother as often as he had done in the past. He felt the deterioration was ‘the thread of things to come’ and it was hurtful for him to think about the future:

“Well I think partly, I don’t come here as often as I used to. I see her every Saturday. I used to come here every Thursday and well, I’m a bit embarrassed to say that I don’t come here every Thursday now, because I don’t like to see her like this. You know you see so many other people here, that are unfortunately far worse than her, and it’s, I suppose it’s possibly the thread of things to come, so I suppose I just distance myself a bit, you know – shouldn’t, but we’re all human aren’t we? So we do things like that.” (Adam, son)

Another relative commented:

“I used to run away. I stayed away, you know, I can’t take it.” (Nathan, son)

As discussed earlier, the person with dementia had sometimes completely changed and the deterioration was very upsetting for relatives to see. The son of a resident described his mother as having been a very energetic and vibrant person and there was nothing of that left now and family were reluctant to visit because they could not bear to see her as she was now:

“Her brother and sister-in-law come occasionally to see her. They are so distressed to see her in the state that she is and the fact that she doesn’t really recognise them, they seldom come. They find it too upsetting and she has one other sister-in-law and she also has only been once or twice for the same reason – they just find it too upsetting to see her, because my mother was a very vibrant and energetic lady and you know, full of beans and to see her as she is now, is really not to see her at all...It’s taken a grandparent away from my children - they only come very occasionally, because they find it very distressing.” (Samuel, son)

The daughter of another resident described how she found it difficult to visit her mother alone; she needed someone else there to support her:

“It’s affected me very, very badly. I find it easier when my brother and I come together, because we’re a crutch for each other.” (Emma, daughter)

Denial was a coping mechanism sometimes employed by relatives - denying or refusing to admit that there was anything wrong. Emma, quoted above, described how difficult it had been for her initially, as her brother had been in denial and therefore had not offered any support to their mother. She had been left with the full responsibility of caring:

“I had a very bad time with my mum’s brother, who said there’s nothing wrong with her and he didn’t want to accept it.” (Emma, daughter)

Lastly humour was sometimes found to be effective:

“Well it’s upsetting obviously you know. You just have to deal with it, but no one likes it. I tend to make jokes of it – that’s how I deal with it.” (Jonathan, son)

(9.2) Views about information and support received

The levels of informal and formal support received impacted on the experiences and coping abilities of relatives caring for people with dementia. Support received by relatives also impacted on the experiences of people with dementia, since it contributed to the quality of care provided and the length of time that relatives were able to continue to care. Few relatives felt empowered by receiving the information and support they needed to support them in their caring role.

(9.2.1) Organisational/professional and service user power levels of empowerment

The lack of information and support was largely due to disempowering practices and attitudes at the level of the organisation. These impacted on the level of power relatives held as service users. However, it should again be mentioned that some of the issues discussed below may have impacted on and been influenced by other levels of empowerment. It should also be clarified that although this level refers to professional support, friends and family members may also be perceived as carers and therefore informal support is also discussed under this heading.

Informal support

With regard to levels of informal support received, relatives described family members as supportive and helpful:

“I had a good family and my daughter took her for a big part of it as well, in helping out. If I was away or anything she would sort of step in and help my mother.” (Norma, daughter)

But not necessarily finding other people, such as friends, as supportive as they would have hoped. Friends did not always understand how they were feeling and they often felt bad about offloading their problems onto them. Sophie, the spouse of one resident, described

how isolated she felt, as she did not feel able to talk to her friends about her situation and feelings and she now felt she had little in common with them:

“I mean I’ve got very good friends, but my life is so different from theirs, my thoughts are very different from theirs. If my husband was suddenly taken ill, they would all be very concerned and very – but it’s been going on for so long now, they don’t realise that I’m suffering. And you can’t tell people you are, I mean they don’t want to see you as a miserable face.” (Sophie, wife)

Others sometimes had little experience of dementia and therefore lacked understanding and knowledge about it and had little empathy with what they were going through, how they were feeling or how bad the situation actually was. Comments included:

“You’re helpless, because there’s no understanding. You can’t say to somebody oh that, because they don’t know what you’re talking about, for example, they don’t understand anything.” (David, husband)

“Nobody seemed to know – now I realise what it is, nobody outside seems to know the extent of it. They say they’ve heard about it. They know of it in theory, that sort of thing.” (Nina, wife)

It was also suggested that some friends may not know how to help, or may feel awkward and find it difficult to cope themselves:

“Some friends are better than others, but some people can cope with things, not everyone can cope with these things.” (Sophie, wife)

Formal Support

Nineteen out of the 28 relatives interviewed spoke of needing information and support from care services. Reasons for others not requiring or wanting it included having a close family member who was knowledgeable about dementia and able to provide the information required; relatives not wanting to expend the extra time going to, for example, a support

group; not wanting strangers in their house; feeling it was their responsibility alone to care; or that they did not need help because they provided limited support to their relative. Only four of these 19 individuals described feeling empowered by receiving the levels of information and support they needed to maintain their wellbeing, quality of life and enable them to cope with the pressures of caring. As mentioned, support was often an important factor in enabling relatives to care for longer, as caring was stressful and difficult – sometimes much more so than had been anticipated. Jootun and McGhee (1998) suggest that carers are sometimes totally unprepared for the role of caring and the pressures may be far beyond those expected or prepared for. If relatives required additional help to that they were receiving, they often had to self-fund it which was a financial strain. Rachel described the situation when her mother had been living at home. They received two days of day care support a week, although she and her family had to fund her mother's transport to the centre and back and they had to self-fund additional support, however it was still not enough:

“We received very little support. Very little. We did pay, out of my mother's – my mother had some savings – we paid for some help. But the help that we had couldn't be enough, because sometimes she was up for 24 hours a day. The only help we got from Jewish Care was 2 days a week at a day centre, which we had to pay for – neither my sister or I drive, so we had to pay for – my sister had to take her in a mini cab and bring her back in a mini cab. Yes, so she had just 2 days a week, but I think we could have done with more.” (Rachel, daughter)

Olivia, the wife of a resident, spoke of problems she had experienced obtaining adequate support and help from her local council. She felt that local authorities and people generally did not acknowledge or realise the stress and strain caring could incur and that it was unfair to be asked to self-fund additional support, when she could not afford it:

“Very little support. Some from X Council, but not anything that I could say was of great assistance to me. I had, eventually - there was one gentleman from the council who came and dressed and washed my husband and shaved him in the morning. And I had a carer who would come and take him for a walk twice a week for 1 hour. There was nothing else available. And there was an Alzheimer's centre

in Y, where Jack could go once a week. I think it was once a week. – Yes - for a few hours in the day time, which would give me a chance to shop, do my shopping. But that didn't last very long because he was getting very bad. They said that was all the support that I could have. They said I was comfortable enough to have private – which I wasn't. I asked X Council – and then you have to pay a little bit. I mean it's nominal it's true, but it's nothing for nothing. I don't think, in general that people know the stress that this puts on a human being. They can only take so much. I do think there needs to be a lot more support.” (Olivia, wife)

Financial difficulties were an issue for several of the relatives interviewed. Those who were better off received higher levels of support, as they were, for example, able to fund full-time private carers.

Support and information were especially important at the beginning, although were often lacking. Relatives sometimes felt powerless, as they did not know what was happening and how to deal with and cope with the situation. They needed information about dementia and issues relating to caring for the person with dementia and advice on how to communicate with and respond to them. They were also in need of much emotional support, although did not always receive it. Comments included:

“I don't know what to do for her – I don't know how to help her. I only know her physical needs, but her mental needs – I'm not very good because when she does open up to me no one's told me what to say or how to cope with it and I don't know what to say.” (Nicole, daughter)

“You don't know how to talk to somebody when they're behaving aggressively like she was. We didn't know how to talk to her. We wanted to know how to communicate with her. We didn't know who to ask.” (Norma, daughter)

“I don't know what to say to her. I don't cope very well emotionally.” (Emma, daughter)

The lack of knowledge was sometimes harmful to wellbeing. Because relatives did not always understand why the person was acting in the ways that they were, they sometimes blamed them and became angry with them. The husband of a resident described how he had gradually learned about dementia by spending time with his wife. Initially he had frequently lost his temper with her, although now realised she was not to blame:

“I didn’t realise what the full extent of Alzheimer’s disease is. Nobody told me. By being with her, I’m gradually learning things, things which used to make me lose my temper...I gradually absorbed the knowledge that it’s not her fault at all, I began to realise it’s my fault, over anxious, you see. I shouldn’t lose my temper...”
(David, husband)

Placement of the person with dementia in a residential home was another critical period, when next of kin said that they would have liked more support. This was often very traumatic time. Isabel, the daughter of a resident, commented:

“I would have liked to have been introduced in advance, if possible, or certainly as it’s happening, to the kinds of things that I could be feeling and the kinds of things that you have to deal with and maybe haven’t dealt with before.” *(Isabel, daughter)*

There are a number possible reasons for carers not receiving the support that they needed, issues as mentioned which relate to the professional/organisational level of empowerment, although some may reflect funding and legislative issues at the societal inclusion level. One explanation identified by carers was a lack of resources and commitment to supporting people with dementia and their carers in the community. A lack of understanding of the needs of carers is another possible explanation. Sometimes there seemed to be little awareness of the type of support required by relatives, for example, relatives described needing more support at the beginning of the illness and on admission of the person with dementia to residential care. Twenty-four hour support was not available and one relative felt that this was important for carers. Organisations which provided help and support were usually only open or contactable during the day, but help was sometimes required outside office hours:

“The one thing I would have liked for other people, really, which I suppose I thought I lacked, is some kind of help line or phone line or support line that actually existed outside office hours. It’s all very well being able to say ring the Alzheimer’s Society during day hours and they you know – do a wonderful job, but it, you know, tends to be 11 o’clock at night that you’re really desperate and you feel that there’s – no one you can turn to.” (Isabel, daughter)

Delays in obtaining services sometimes occurred as a result of huge numbers of forms that relatives were required to complete, by which time they were often at breaking point. The husband of a day centre member described how he had been asked to complete countless numbers of these in order to obtain some respite and how exhausted he felt, as he had not been able to have a break for a long period of time:

“The trouble is, every time you ask for support, you get more and more forms. I was told you can have six weeks respite a year and when I got in touch about it I got a form with about 30 pages to fill out – they want to know your life history! These forms – it’s just, they’ve sent me an income support form, I’m not asking for income support. Originally he sent me a housing flaming benefit form and a council tax flaming form. I had got all these forms to fill out. It turned out I didn’t need the housing claims form or the housing benefit form. There were that many forms, it was just getting me down – what do they want me to fill all these forms out for if I’m not claiming these things. It caused me a lot of agro and I’m not there yet, so I’m still trying but I need a break. The last time I had a break was October 1999.” (Caleb, husband)

There was sometimes a lack of acknowledgement of the caring role, the pressures that carers were under and the work that they did. Problems were sometimes experienced with receiving benefits. One spouse described not receiving any carers allowance, despite caring for her husband for 10 years, because it was not granted over the pensionable age:

“I don’t get carers’ allowance. I have been a carer now for 10 years and I’ve never received a penny because I’m over the pensionable age. That’s what I’ve been told

but I have tried to fight it and they said there's a new rule out now that you can get in before but it hasn't been passed by parliament yet." (Deborah, wife)

Organisations sometimes lacked understanding of dementia and its effects on the person with dementia and their carer, which sometimes prevented them from granting adequate help or benefits. It was sometimes extremely stressful, on top of everything else, for relatives to have to fill in forms and go to tribunals to claim what was rightly theirs. If they chose not to fight or were unable to, then they had to live without. The wife of a resident commented:

"I had a bit of trouble with the benefits agency, when my husband had to give up work and everything. They didn't regard Alzheimer's as an illness that stopped people from working. They said it's a degenerative disease and we can't give you this benefit. Anyway I was going to go to a tribunal and then they changed their minds. But it was very frustrating what forms you have to fill in. And it's embarrassing if people don't understand...I also got annoyed with disability organisations, which were for sensory and physical disabilities and didn't understand that there were people that didn't come under that qualification so they weren't part of that organisation. I wrote a note to them about it saying you shouldn't give the name that your organisation is for people with disabilities if you don't include mental disabilities or dementia disabilities as well." (Sophie, wife)

A common problem which prevented carers from obtaining information and support was not knowing who to approach, as support was not openly offered but had to be actively sought out by relatives. Comments included:

"I only received support and information from the unit, where my mother was getting treatment and that's because I asked for it, but nobody ever sort of gave me any information at all." (Jonathan, son)

"You have to find out everything. Everybody has the same complaint. Nothing is very forthcoming. You do have to find out these things." (Rachel, daughter)

“We have information. We have to fight to get the information. We only discovered quite by chance, very recently that she had um, a form of dementia, which was caused by mini-strokes that she had. When she moved here, they referred her to a social worker here actually, they mentioned it in passing and actually we’d never been given the diagnosis.” (Anna, daughter)

GPs who were often the first point of contact sometimes had limited knowledge of dementia and did not always offer a great deal of support. The daughter of a day centre member described visiting the GP, as she was very concerned about her mother’s memory. She described the GP as having little knowledge of dementia and offering no assistance:

“The GP didn’t offer any assistance at all. He asked her what year she was born and some political question from years ago, and she knew it. He said there’s nothing wrong with her memory but that’s nonsense, we know she remembers all that from years ago, it’s now, her short term memory.” (Alana, daughter)

Support was available, but relatives had to fight hard to obtain it and actively pursue it and if they were not able to do this, then they were left without. Those who received more support felt lucky to be able to speak-up for themselves and seek out the help and information they needed. Comments included:

“I actually work professionally in information, so I’m very attuned to ringing up and getting information and sorting things out. I sometimes feel that if I wasn’t quite so active and busy on the phone and sorting things out, I don’t know quite what would happen.” (Isabel, daughter)

“I’m lucky because I’m able to talk for myself on the whole. There needs to be a lot more support. Because as I say, I can talk for myself, but there are a lot of people who don’t know anything about it and they are stuck with it and they have no idea. They have no idea where they can go for support, even though the organisations exist.” (Sophie, wife)

“I had someone very close that could give me any information that I asked for, so it was very easy for me. Perhaps other people didn’t really know where to go to get it.” (Norma, daughter)

Although these relatives did access the help they required, the process of obtaining it was sometimes extremely stressful for them. It was an additional pressure and strain on top of everything else which they could have done without. There were mixed feelings about the information and support actually received. Sometimes support received was of little help, as often it was short term:

“An Admiral nurse from Jewish Care came out, but not for very long.” (Olivia, wife)

Attending support group meetings was not always helpful, as although others were in a similar position, it was felt that there was a lack understanding about what they were going through and how they felt:

“I mean every case is different and everybody feels things in a different way.” (Nina, wife)

Sometimes counselling was of no benefit, because it was felt that it could not “solve” the situation which was becoming progressively worse. It did not always help to talk about it, for example, Sophie, the wife of a resident who was feeling very depressed commented:

“I did actually have some counselling when my husband first came here and my family wants me to go and have some more counselling. I don’t know. I don’t know if it really helps. I don’t think it really helped because the situation is there, it’s not getting any better, it’s getting worse. And who can be with me when I’m alone.” (Sophie, wife)

Counselling and attending support groups were not useful for some but helpful for others. The daughter of one resident described counselling as very useful for learning more about herself and providing her with the opportunity to talk about how she was feeling:

“I got a lot of counselling from Jewish Care, which was wonderful. I can ring up if things get bad for me. If they can’t come and see me somebody will speak to me, um, but I also actually learned a lot from the counselling sessions actually on my own account.” (Nicole, daughter)

A Jewish Care Admiral nursing service was sometimes provided, but again this was not always useful. One relative described feeling challenged by an Admiral nurse and finding her interventions intrusive because she seemed to take her mother’s side, who she felt was covering up all her problems:

“My mother bluffed beautifully when they went to see her, she could bluff her way through anything.” (Emma, daughter)

Sometimes people with dementia were very good at covering up to outsiders and health professionals may not have realised the level of support needed or how bad the situation had become, which was frustrating and disempowering for relatives, who felt that they were not listened to and their views were not taken on board. Others praised services provided by Jewish Care:

“I can’t say enough about Jewish Care – they’ve been wonderful.” (Nicole, daughter)

One relative who had been very active in seeking out her own support described feeling delighted with the services she had received:

“I’ve had a lot of support from Jewish Care and also from the council. I have been extremely lucky in that respect. And as things have deteriorated, I have had support from home support services and from Crossroads. Some people don’t even know that these organisations exist. Once I was in touch with one place, you’d find leaflets and get in touch with other places. I think it was the social worker, who mentioned crossroads to me. She mentioned aids you can get for the bath and for the chairs and things like that to help physically when she came. And a home

worker came to help my husband get dressed in the morning and saw he had difficulty getting up and downstairs and suggested we had a rail put in. So one person has put me on to another, which has been very good.” (Sophie, wife)

In addition, as described in previous chapters, residential and day care services were often valuable in providing a break or support for relatives and improving their quality of life. Although, as described, these services were not always adequate or of high quality.

(9.3) Discussion of findings

In conclusion, relatives of people with dementia were disempowered at virtually all levels of the empowerment model. With the onset and progression of dementia, well being was adversely affected and feelings of loss of control experienced at an individual level. At a societal inclusion level, quality of life was reduced, as the huge pressures of caring resulted in many relatives no longer having the opportunities and the lifestyle they had enjoyed before. Some individuals had developed strategies which enabled them to cope with and gain some control of their situation and feelings, which included avoiding or denying the situation and accepting it and getting on with life. Support and information were also important and had the potential to greatly enhance wellbeing, feelings of control and quality of life. However unfortunately, disempowering practices at the level of the organisation and society resulted in many relatives not receiving the support they needed. A number of reasons were identified for this, which included a lack of resources and commitment to supporting relatives; a lack of understanding of dementia, the needs of carers and the pressures and stresses of caring; and a lack of information and knowledge of where to go for help. The implications of these findings are discussed in chapter ten.

10 CONCLUSIONS, IMPLICATIONS & RECOMMENDATIONS

Results from this study add to existing knowledge in the field, as they show that it is possible to elicit accurate information about services from people in varying stages of dementia and therefore include them in service evaluation. This potentially empowering process may be important when looking to develop services which meet the needs of people with dementia, particularly so since findings reveal that relatives, who have often acted as proxies or informants, are not always able to accurately represent their views and feelings.

There is a need for more research which includes the perspectives of people with dementia, particularly of those people with more advanced dementia and that which incorporates quality of care issues. The results of this study to some extent help to bridge this gap, as much information about dementia and services was gleaned from people of a range of severity of dementia and their informal carers. The data indicate that people with dementia and their relatives felt disempowered at virtually all levels of the empowerment model, suggesting that there are multiple issues which need to be addressed.

This chapter summarises and explores findings from the study and from these makes several recommendations for dementia practice and research. It consists of four parts. Part One outlines the main findings from the study, in relation to the different levels of empowerment. Possible explanations for these findings and the implications and the recommendations arising from them are explored in Parts Two and Three, where a model of empowerment for dementia care research and practice is outlined. Part Four concludes the chapter. It explores the strengths, challenges and limitations of the study and puts forward some suggestions for future research.

(10.1) Main findings from the study

The main findings are discussed in relation to the different levels of empowerment below:

(10.1.1) Empowering the individual

Confirming the feasibility of eliciting information for empowerment purposes

The results show that it is possible to elicit accurate information from people with dementia about services, as their perspectives were supported by the video and observational data. Although a number of studies have attempted to explore the reliability of accounts of people with dementia about their own health and abilities (Snow, 2005; Phinney, 2002; Wadley et al, 2003), research in this area is extremely limited. The findings lend some support to a recent study by Whitlatch et al (2005), which took into account the views of 111 people with mild to moderate dementia, and found that they were accurate and reliable in their ability to respond to questions about demographics and basic preferences. However, the results go further as they demonstrate the potential to obtain dependable views about services, which adds evidence to support claims that people with dementia can be active participants in service evaluation (Proctor, 2001; Reid, 2001). A particularly significant finding from this study is that accurate information is obtainable from people of a range of severity of dementia, that is, from people with more advanced dementia, as well as from those in the early stages.

The results suggest that particular techniques and importantly a commitment to communication are important in order to obtain perspectives and feelings from people in different stages of dementia. Communication was invariably more difficult with people with more advanced dementia and involved a greater reliance on non-verbal methods, a willingness to look for meanings behind what was being said, make links in words and so on. Arguably, since it is the attitude and skills which are important, the methods used are transferable to other contexts and could also be useful when looking to communicate with people with dementia in a general sense, either inside or outside a care setting.

In keeping with the empowerment literature, findings suggest that treatment of and attitudes towards the person are important and can influence communication. In order to maintain self-esteem, trust and enable the person to feel comfortable to disclose feelings and information about their personal circumstances, the establishment of a good relationship was crucial. It was important to be respectful, non-judgemental and avoid making the individual feel inadequate because they uttered the wrong word or could not recall a particular word, an approach which has been recommended by Crisp (cited in Adams and Clarke, 1999). Accepting the emotional reality of the world of the person with dementia was also vital to obtaining the data which is central to this study. Some people thought they were much younger than they were and that their parents were still alive. It was important not to negate what the person had said, but to accept how they felt and what they believed to be true. Feil (1989) suggested it is important to respect the person's choice to live in the past or present and to empathise with them and acknowledge and validate their feelings.

A willingness to share power with participants was integral to a trusting and 'equal' relationship and to create an empowering environment. This was achieved in a number of ways, for example, it was effective to allow the person to take the lead and have some control over the interview, by using broader, open-ended questions. Tappen et al (1997) and Jonas-Simpson and Mitchell (2005) have also incorporated this approach, which allowed individuals to introduce topics they were interested in, wanted to talk about and felt comfortable with, which could then be followed up. It was important not to pressurise the person, but allow plenty of time and space for them to disclose the information they chose to in their own time. As anticipated, specific or closed-ended questions, in which people were asked to provide a particular piece of information, or a "yes" or "no" answer were less effective, as they generated less information and were sometimes distressing for individuals. In addition, answers elicited with these types of questions were less likely to be supported by the video and observational data; broader, open questions clearly enabled individuals to be more open about and disclose their true feelings. Additionally, it was important to work in partnership with participants, for example, when establishing the best time and place for interview and methods and a willingness to be flexible, adaptable and take account of individual needs was crucial.

The results suggest that particular skills are necessary to maximise communication with people with dementia. For example, I found it important to be aware of and attuned to suggestions that the language of people with dementia may contain symbolic and metaphorical connotations, analysis of which may provide further insight into what the person is experiencing and how they are feeling (Killick, 2005). As anticipated, confabulatory story telling was a feature that sometimes arose when interviewing people with dementia in the study. At times, people with dementia related stories that appeared not to be true, however these were not disregarded as nonsensical, but often gave interesting insights into the individual's life and about the way they were feeling and they may have helped to preserve self-esteem. It was important to look for meanings behind what was being said, in order to make sense of what the person was communicating, a finding which has consequence for care of and general interaction with people with dementia. A lack of time and knowledge of this issue may result in the views of people with dementia not being listened to or taken on board.

Mirroring the literature in the area (Goldsmith, 1996; Proctor, 2001; Lloyd, 2004; Adams and Clarke, 1999; Allan, 2001), I found listening carefully to the words of people with dementia to be essential. It was also sometimes helpful to make links in words and use pictures, scales and third party approaches, particularly when interacting with people with more advanced dementia. Video and observational data provided useful supplementary information to the interview data, as by observing and filming the day-to-day lives of people with dementia, feelings and views about services were elicited and additional information was often provided, which was particularly useful if the person with dementia had forgotten how they felt about a certain aspect of a service when interviewed. Non-verbal cues helped to make sense of what the person was trying to say.

The techniques used in this study are not confined to the research process but can be employed in different situations and for different purposes. They have allowed a rich seam of data to emerge which can be used to underpin empowering practice and to address gaps in services.

Summary of communication techniques
<ul style="list-style-type: none"> • Establish a trusting relationship – involves empathy, respect, acceptance, a willingness and ability to listen actively
<ul style="list-style-type: none"> • Work in partnership – entails consultation, e.g. about methods, time and place for interview; enabling participant to have control over the research process; maintaining an equal relationship as far as possible
<ul style="list-style-type: none"> • Develop own skills and knowledge – useful is the ability to make links in words; look for meanings behind narratives; use different methods, e.g. pictures and scales. Good observational skills are essential, as well as an ability to listen effectively
<ul style="list-style-type: none"> • Personal characteristics/attitude – patience, non-judgemental attitude, commitment, flexibility and adaptability

Impact of the experience of dementia on the individual level

The study set out to investigate experiences of dementia from the perspectives of individuals with dementia, a relatively under-researched area which needed further exploration. The perceptions and feelings obtained are generally consistent with the existing literature (Keady & Nolan, 1995; Gillies, 2000; Ostwald, 2002, Bryden, 2005, Holden, 2005). For example, echoing findings from this study, Gillies (2002) interviewed 20 people diagnosed with dementia. Informant accounts highlighted the impact and frustrations of living with memory difficulties and the accompanying feelings of incompetence, failure and low self-esteem. In her recent book, Bryden (2005) recounts her personal experiences of dementia and in keeping with narratives of participants in this study, she describes the loss of independence and the difficulties she experienced with communication and memory.

Particularly evident in this study were the overwhelming feelings of loss and multiple losses described by people with dementia themselves, which impacted on and influenced the individual level of empowerment in a number of ways. Participants described the loss

of cognitive skills, such as memory and communication which resulted in feelings of loss of control, self-confidence, inability to articulate views and in disorientation and confusion. They recounted how the loss of mobility, driving and personal care skills, also resulted in feelings of powerlessness, low self-esteem and influence. The findings contribute to the growing body of literature on the subjective experience of dementia.

The study also examined relatives' experiences of dementia and empowerment and these findings also mirror the existing literature (Zarit et al, 1998; Jootun & McGhee, 1998; Kosmala & Kloszewka, 2004, Cuijpers, 2005). For example, results from Almborg et al's study (1997), which took into account the experiences of 46 family carers, highlighted the major strain endured as a result of behaviour and memory changes in the person with dementia, feelings of loss and acquisition of a new role. Davis (1996) describes the numerous stresses experienced by carers, including decline in physical health and wellbeing, feelings of social isolation and depression. In a review of the literature exploring health differences between carers and non-carers, Pinquart and Sorensen (2003) found that carers were more likely to experience higher levels of stress and depression and lower levels of subjective wellbeing, physical health and self efficacy.

Relatives in this study described their experiences of dementia as devastating and extremely stressful, also referring to the immense psychological, social and physical pressures endured. They described how the experience of a relative developing dementia impacted immensely on their wellbeing. Feelings of distress, isolation, depression and guilt were commonly experienced and they often felt they had little control over their circumstances. There seemed to be little they could do little to help the person or ease their own pain, to which it seemed there was no end.

Individuals with dementia and their relatives reacted to their experiences in different ways and experienced personality and behavioural changes as a result of dementia. It is argued that aggressive, withdrawn or obsessive behaviours which are often attributed solely to the disease, have psychological and social components (Bender & Cheston, 1997; Trilsbach, 2002; Ragneskog et al, 1998; Watts, 2003). The data suggest that such behaviours might have been responses to the changes experienced and reflected the way the person felt inside. The informant narratives highlight a number of different strategies which were

employed by individuals with dementia to help them to cope with and gain some control of their situation. These mirror the existing literature described in chapter three (Bahro, 1995; Keady & Nolan, 1995; Clare, 2003; Norman, 2004) and included using memory aids, keeping actively involved and busy, denying difficulties and withdrawing from situations and people. Relatives experienced various levels of pressure and stress, and used a variety of coping strategies which are again broadly in keeping with the existing literature (Almberg et al, 1997; Norman, 2004). For example, consistent with findings from the study, Almberg et al (1997) found that carers employed mainly emotion focussed and problem solving strategies which included avoidance or wishing the situation away; acceptance and seeking help and support. Similarly and also paralleling study findings, Norman et al (2004) identified acceptance and denial as common coping mechanisms employed by relatives.

(10.1.2) Disempowered by the organisation

The changes and losses experienced by people with dementia may have restricted and limited empowerment to varying degrees, depending on the person's skills and abilities. However the data revealed that despite these difficulties and impairments it is still possible to empower people with dementia, if appropriate techniques and attitude are adopted. The results show that other people's behaviours and/or organisational practices can influence empowerment at an individual level.

The findings unequivocally demonstrate that people with dementia felt disempowered by the lack of choice, independence, communication and stimulation in some of the care homes. These results offer an increased understanding about care for people with dementia *from their perspective*, as to date there has been little research conducted in this area. The findings echo those of one of the most recent and comprehensive carer led studies in the UK (Train et al, 2005). Train et al (2005) explored the experiences of 21 people with dementia and also relatives and staff about long-term care and included long stay psychiatric wards, nursing homes and voluntary, private run and local authority residential homes. Train et al's study also identified the importance of activity, the need for choice and better lines of communication between residents, relatives and staff. The findings of this research are similar to observational studies, which have identified inadequate levels of

stimulation and a lack of autonomy (Nolan et al, 1995; Ballard et al, 2001; Edwards et al, 2003; Goffman, 1961). They are not dissimilar to the findings of Ballard et al (2001) who used dementia care mapping to evaluate the quality of care within private sector and NHS care homes and found them to be far from satisfactory. Care practices within the residential settings in this study were generally inconsistent with a psychosocial approach, adhering more to a biomedical model. Moreover, they did not meet the standards set out by current legislation (National Service Framework for Older People, 2001; National Minimum Standards for Care Homes, 2002), which emphasise the importance of user empowerment, involvement, stimulation and person centred care.

Conversely the study found that practices within day care services were more empowering. According to the service users the quality of care in centres, and particularly in specialist day care services, was perceived to be much better than that in residential and nursing homes. Members really valued the increased opportunities for interaction, activity and independence and care approaches tended to person centred and requirements of current legislation better met. Although literature and policy guidelines constantly reiterate the importance of these elements, this study affords knowledge from the perspective of people with dementia. The results generally mirror findings from the few studies conducted in this area, which have attempted to examine the effects of day care attendance on people with dementia, either through interview or observational methods (Reid et al, 2001; Coombes et al, 2004; Curran et al, 1996; Kim et al, 2002; Woodhead, 2005). In line with findings from this study, they have suggested that attendance has a positive effect on wellbeing. For example, Coombes et al (2004), who interviewed three younger people with dementia about a local day hospital service, reported that all three participants valued the support they received enormously. Similarly, Reid et al (2001) explored the experiences of 19 day care attenders and found that on the whole, participants were very satisfied with the service. In keeping with findings from this study, they enjoyed the company of other members, the activities, liked the staff and felt comfortable about voicing concerns.

The data show that people with dementia were also sometimes disempowered by attitudes and behaviours of family members and friends. As in residential services, communication and control were issues and contact with friends and family members was reduced. Reflecting the work of Werner (2005) and Kitwood (1997), which suggests that people with

dementia may experience behavioural discrimination or social distance, where contact with them induces anxiety and is therefore avoided, they distanced themselves, because they were unable to cope with the changes, sometimes leaving the person feeling isolated and abandoned. For reasons of safety and convenience, the behaviours of relatives and friends also sometimes restricted autonomy and independence and for example, people with dementia were sometimes locked into their homes or moved into a care home. The narratives of both people with dementia and their relatives highlight the tensions which arise between risk and empowerment. It may be difficult to empower and maintain safety simultaneously, but the data suggest that risk took precedence over empowerment. Taking both issues into consideration and achieving a balance would be important to maintain maximum wellbeing of the person with dementia.

The study also explored how relatives perceived care provision for people with dementia and whether or not their views were congruent with each other. The data challenge existing beliefs that relatives' perceptions are accurate, but support more recent suggestions (Kemp et al, 2002, Brooker, 1997, Cottrell & Schulz, 1993) that they may not always have accurate knowledge about services and the perceptions and feelings of people with dementia. In the residential phase, relatives' views differed considerably to those of people with dementia, but these were contradicted by the video and observational data, which instead confirmed the perceptions of people with dementia. The study findings therefore highlight the importance of seeking the views of people with dementia themselves.

Relatives also sometimes felt disempowered at the level of the organisation. Current legislation (National Service Framework for Older People, 2001) highlights the importance of involving informal carers by providing information and advice about the health and welfare of the person they are looking after (subject to consent from the older person), inviting them to participate in CPA meetings and so on. This, it says, may enable relatives to become partners in care and result in a better quality of life for the person with dementia. However in the residential homes particularly, relatives did not always feel involved, which perhaps reflects a lack of time, or awareness of the importance of involving informal carers, on the part of staff. In addition and supporting studies of Pickard and Glendinning (2001), Teel and Carson (2003) and Jootun and McGhee (1998), those relatives caring for someone with dementia in the community did not always receive the information and support they

needed to support them in their caring role. The results suggest that policy which requires that appropriate support is provided to carers, following a needs assessment (Carers and Disabled Children's Act, 2000), is not being effectively implemented.

(10.1.3) Dementia : loss of influence and control

The experience of dementia impacted on the service user power level of empowerment, as levels of independence and autonomy deteriorated and the disease progressed. Individuals with dementia could not or were not permitted to do many of the things they used to do, such as wander outside freely, drive or stay in their own homes and they lost control over their lives, as they were forced to accept help with things they were accustomed to doing by themselves. With the onset of dementia, relatives also experienced feelings of loss of control over their lives and the lives and welfare of their loved ones – see 9.1.

The low levels of control within residential settings served to further reduce empowerment at the service user power level. As mentioned there was a lack of choice and independence, residents sometimes felt confused in the larger, busy environment of the homes, they were frightened to complain and so on and relatives felt disempowered by the lack of information, communication and consultation. In day care services higher levels of influence were described and observed, however involvement remained at a lower level and did not extend to participation in higher decision making processes. Standard one of the National Service Framework for Older People (2001), which is concerned with 'rooting out age discrimination,' requires that older people are represented and consulted in every organisation, but there was little evidence of this in the settings investigated. In addition, a number of relatives had difficulties accessing information and support in the community and feelings of powerlessness and loss of control were experienced as a result of this. They did not always know how to deal with their situation and respond to the person with dementia and it sometimes reached a stage when they felt unable to cope any longer.

Results show a disparity between legislation and practice, as a government priority has been to maximise service user influence and control over services, as well as provide person centred, individualised care (NHS Plan, 2000; National Minimum Standards, 2002; Carers and Disabled Children's Act 2000 and Carers (Equal Opportunities) Act 2004

combined policy; The green paper: 'Independence, choice and wellbeing,' 2005). The care and support described did not meet the standards set out by these policies.

(10.1.4) Societal exclusion

Many of the experiences described resulted in reduced quality of life and opportunities for relatives and people with dementia at a societal inclusion level. These findings again conflict with current policy (National Service Framework for Older People, 2001; Carers and Disabled Children's Act, 2000 and Carers (Equal Opportunities) Act, 2004 combined policy; Independence, wellbeing and choice, 2005), which emphasises the importance of the provision of a high quality of life, equal rights and opportunities for people with dementia and their carers. The findings may partly be a product of wider societal factors, e.g. a lack of funding and resources for older people, ageism and stigma, issues which make it very difficult for this group of people to empower themselves. Further attention is given to these later on in the chapter.

(10.2) Findings explored

Findings of the study and possible explanations for these are explored in greater depth below:

(10.2.1) Relatives' views no substitute for those of people with dementia.

One of the most significant findings of the study relates to the discrepancy between the views of people with dementia and their carers. The findings show that relatives do not always have a complete and accurate knowledge about services for people with dementia and know how they feel about them. A number of reasons were identified for these findings, which were detailed in chapters 6 and 7 and include, relatives having difficulty communicating with people with dementia, in the residential phase particularly; them spending little time in care settings; being grateful for the support received; and in denial of adverse aspects of care.

In the past, people with dementia have been disempowered, as their perceptions and feelings have been ignored, while relatives have been asked to speak on their behalf (Adams & Manthorpe, 2003). However, the finding that relatives' views were often unreliable and those of people with dementia more dependable, questions the appropriateness of seeking their views, while omitting those of people with dementia. The results suggest the need to approach people with dementia themselves to find out their views about services.

(10.2.2) Quality of care issues

Lack of stimulation and communication

A lack of resources may have contributed to the lack of stimulation and communication in residential and community day care settings, for example a lack of staff was mentioned by a few of the relatives, however it was more evident that care staff did not view non-physical care as part of their job. In interviews carried out as part of the wider project (Vass et al, 2002), staff indicated they considered that this was the role of the activities co-ordinators, who are employed by Jewish care with a particular responsibility for organising activity within the home. Normally there is just one officer for the entire home, which is not sufficient, particularly in a larger home where residents have differing levels of ability and need and this could explain the lack of activity in residential settings. Despite an emphasis on activity and stimulation in current policy (National Minimum Standards for Care Homes, 2002; National Service Framework for Older People, 2001), care practices were very task orientated, communication viewed as secondary and social interaction often perceived to be unimportant and not part of the carer's role. For example, one carer, interviewed as part of the larger project, said others perceived her to be lazy if she took time to sit and talk to a resident (Vass et al, 2002). This may reflect the culture within the home, which is one of 'getting through the work,' not 'sitting and doing nothing' (Kitwood, 1997) and suggests a lack of training in person centred approaches and communication skills. However, the data suggest this was only one aspect of the problem.

Staff, particularly those in residential settings, also spoke of the multiple demands on their time and the difficulty of combining a caring workload with more socially orientated

engagement with residents (Vass, 2002). However, cross-referencing of the interview with video data revealed that staff in residential settings were sometimes seen to have spare time but choose to spend it in other ways, which did not include individuals with dementia, for example, they would be reading the newspaper or conversing among themselves in the corner/back of the room or in the staff office. Staff may not have viewed organising activity as part of their role, but it was equally evident they did not want to interact with people with dementia on a social basis. This suggests some degree of communication difficulty. Communicating with people with dementia is not always easy. As was conveyed by staff in the larger project to which this is attached (Vass et al, 2002), problems are frequently experienced, suggesting the need for more training in communication and interpersonal skills. This last point may also be applicable to interactions between people with dementia and friends and relatives. Difficulty with communication could explain why people with early onset dementia and other people sometimes distanced themselves or wanted minimal contact with those in the more advanced stages; they did not know how to relate to them. It is also possible that they perceived those with more advanced dementia as frightening or strange in the way they behaved or looked, reflecting the discomfort in society in dealing with deviations from 'normal' behaviour (Werner, 2005; Kitwood, 1997) and resulting in minimal interaction and communication with these individuals. In day care settings where staff had more training in communication and person-centred approaches and where people were in earlier stages of dementia, levels of interaction were much higher.

The lack of social interaction identified may also relate to staff and other people wanting to remain emotionally distant from individuals with dementia. Interview data revealed that relatives and friends sometimes found it very painful to witness the deterioration in the person's condition and avoided contact for this reason. In addition, in interviews carried out as part of the wider project, staff indicated that they felt that becoming too close or attached resulted in them becoming more emotionally vulnerable within their work (Vass et al, 2002). Thus focusing on the practical aspects of care, while neglecting the psychological and social tasks, may serve as a defence mechanism, which operates to protect care staff from what may be highly anxiety provoking situations. It can help protect staff against confronting their own individual aging, loss of self and death (Kitwood, 1997). In addition, and reflecting literature suggesting that formal carers may experience high

levels of stress and burden (Brodarty et al, 2003; Sourial, 2001; Gandoy et al, 2004), caring both physically and emotionally was described to be very exhausting and stressful, whereas doing just one or the other was easier to cope with (Vass, 2002). Caring for someone with dementia requires much skill and stamina and care staff need to be able and willing to invest themselves in this demanding role, which calls for adequate training, support, supervision and working conditions (Loveday, 1998; Stone, 2004; Little, 2005; Heid-Grubman, 2005). Racist attitudes may also be a contributing factor, as some service users were racially abusive towards staff and there is evidence to suggest it had not been addressed adequately, compounding the problem. In interviews conducted as part of the wider project, staff described finding this very difficult to cope with and although not acknowledged, it may have resulted in a reluctance on their part to interact with some individuals, other than on a very basic level. It may be beneficial to explore this area further, as although there is much useful literature on transcultural care/working (Papadopoulos et al, 1998; Purnell & Paulanka, 2003), the focus of this is on supporting and meeting the needs of service users. There is limited literature which takes account of the support needs of staff. Supporting work of Calkins (2005) and Blackman (2003), the results suggest that environmental factors may also have hindered communication, for example sometimes there was much background noise, such as loud music from the stereo or the television. The type and layout of chairs at times hindered communication as it was difficult to see the person next to you and individuals were sometimes seated with people they did not feel able to relate to or communicate with.

Low levels of control and influence

The lack of choice and independence identified in residential settings and sometimes in people's own homes may reflect the need for convenience or speed, as it was simply quicker to make decisions and to do things for people with dementia, than allow the person the time to do it for themselves. In addition, the institutional nature of the residential and nursing homes was very disempowering for residents. The video observations demonstrated some of the features described by Goffman (1961) and Townsend (1964) over forty years ago, in that there were barriers to the outside world and all aspects of life were conducted in the same place and under the same authority. Although there is a need to ensure residents are safe, it is arguable that security needs to be so tight and discipline so

rigid. In addition, people did things collectively, so that individuality was lost or ignored, everything happened to schedule and there were a multitude of rules and regulations and through this a loss of autonomy. This may explain claims of some relatives that the person with dementia did not always see a doctor or another healthcare professional when they needed to or they were not taken to the toilet when they wanted to go. There were specific times for things and there needed to be batch of people needing, for example, an optician before one was called out and in this way individual needs and wants were sometimes overlooked. Environmental factors may also have contributed to a loss of control, for example, some of the homes were very large and residents felt confused, lost and frightened.

Staff attitudes and behaviours, at the level of the organisation, may have hindered empowering practises. Staff are often reluctant to share power, to listen to service users and to accept criticism (Honey, 1999; Henderson, 2003), and this may be a reason for the lack of involvement of people with dementia, but may also partly explain the lack of interaction, communication and consultation with relatives, mentioned in chapter six. Care staff, particularly those in hospital and residential settings, are usually in very powerful roles and make the decisions and choices, while service users are in subservient roles and merely follow instructions (Muir-Cochrane, 2000; Sayce, 1999). This reflects attitudes that professionals know best, but also high dependency levels, particularly in institutional settings.

The social model of disability provides an alternative or additional explanation for the lack of empowerment. This model suggests that problems arise from society's restrictive attitudes about disability and from the way that other people perceive people with disabilities (Krogh, 1998). These prejudices, which are not always conscious, make it extremely difficult for people with disabilities to assert their rights. They include beliefs that people with disabilities are incompetent, incapable of making their own decisions and choices and dependent on others. People with dementia are in an even more disadvantaged position because they bear a double stigma of having a mental health problem as well as one of old age (Graham, 2003; Gillies, 1997).

The problems identified may reflect a lack of training. Those working with older people are often the least qualified and trained (Valins, 2002; Kings Fund 2001; Hughes, 2000). Empowering and communicating with people with dementia requires high ability and skill and it can be physically and psychologically draining. Adequate training and support are required for staff to be able to provide the highest quality of care for residents, to offer choices and promote independence, but despite aims of the government to root out ageism, older people's services have been persistently given low priority in comparison to services for younger people (Woods, 2000; Kane, 2002, Little, 2005). Apart from the absence of training, work with older people, particularly in residential settings, is not always valued. Wages are invariably very low, turnover is high and staff are not always there because they want to be (Valins, 2002; Margallo-Lana et al, 2001; Heid-Grubman, 2005), thus, they may not be motivated to provide the highest level of quality of care. Support structures are often weak and if staff are not valued and empowered within the organisation, it is difficult for them to value and empower others. Staff who work in a disempowering environment, who are told what to do and are not encouraged to use their initiative are unlikely to empower service users.

Some aspects of care viewed more positively

While there were distinct problems with some aspects of care, others were viewed more positively, for example, the physical environment was perceived to be satisfactory across both residential and day care services. This finding fits within a medical model, which seemed to take precedence in some settings, as much attention was paid to physical dimensions of care, while social and emotional needs tended to be neglected. Cultural and religious needs were also said to be met in all three settings and this is to be expected of Jewish Care services which specialise in providing care for Jewish people and meeting their needs. Kosher food was provided and Jewish festivals and religious events were always celebrated.

The high levels of satisfaction with day care services can be explained in different ways. People who attended day care centres were, on the whole, in earlier stages of dementia than those in residential care, so communication problems and stigma were probably less and staff may have felt better able to interact and communicate with members. Day centre staff

reported, in interviews carried out as part of the wider project (Vass et al, 2002), low numbers of members who were unable to communicate verbally with them. The higher levels of control and influence may be a result of people with dementia being perceived to be more competent and able than those in residential care. In addition, the centres in this study were not as institutionalised as homes, and therefore the environment less disempowering, with a greater potential for choice and independence for members. Power imbalances were not as prominent and no one said they would feel afraid to complain. Although practices were more empowering within day care services, involvement took place at a lower consumerist level and there were no opportunities for involvement in higher decision making processes.

Special day care centres were perceived more positively than the community centres and reflect them being much smaller, with a higher staffing ratio and a structured programme of activity developed especially for people with dementia. Centres catered to the individual needs of people with dementia, offering choices with regard to food and activity and staff had more training in dementia care and in person centred approaches. Special day centre staff, interviewed as part of the wider project (Vass et al, 2002), referred to a range of non-verbal forms of communication, including body language, facial expression and eye contact, suggesting better skills and ability to communicate with people with dementia. However, in contrast, community centres catered for older Jewish people generally and not specifically people with dementia. People with dementia often felt lost in community centres, their needs were not met, activity was sometimes unsuitable and staff were less likely to be able to relate well to people with dementia. The experience in community centres was broadly similar to that in residential settings. It is feasible to transfer some of the aspects of good practice in special day care services to residential and community day care services and this would almost certainly result in a higher level of empowerment within these services.

(10.3) Implications for policy and practice

The findings reveal that people of a range of severity of dementia are able to articulate clear and reliable opinions and feelings about the care they receive, which suggests it is feasible to empower them and enable them take an active role in the planning, delivery and

evaluation of services. The benefits of consulting with individuals with dementia are immense and include enhanced individual wellbeing (Cormie, 1999; Melling, 2003); increased knowledge of services; the illness; how dementia affects the individual; and insight into the coping mechanisms they employ to deal with it (Robinson, 2002, Ostwald et al, 2002, McKee, 1999). Thus, care services better adapted and more responsive to the needs of people with dementia can be developed through evaluation (Keady et al, 1995). However, obtaining views from and involving people with dementia is not always straightforward. The findings from the study demonstrated that particular techniques are required, and it is often necessary to use multiple strategies and employ a flexible and adaptable approach. Useful techniques may include broad, open ended questions, pictures, scales and third party approaches. A willingness to look for meanings behind what is said and for non-verbal cues is important, as well as adapting methods to meet the needs of the person concerned.

Although the feasibility of empowering people with dementia has been increasingly recognised over the last decade, there is still limited evidence of this recognition in research and practice. People with dementia, for instance, are not often included in service evaluation (Proctor, 2001) and the results of this study suggest they and also their relatives do not always feel empowered within service settings. Empowering relatives by providing adequate support and information to them is important, to maintain their wellbeing and enable them to provide a high quality of care for people with dementia. Relatives who are under extreme stress and strain are more likely to experience health problems of their own and there is an increased chance of abuse towards the cared for person (Jootun & McGhee, 1998). A greater emphasis needs to be placed on empowerment and this could be achieved by developing a model of empowerment which could underpin dementia research and practice, for example, the framework underpinning this study (see the introduction, pp 9-12) could be used for this purpose:

(10.3.1) Enhancing individual wellbeing, skills and abilities

At the first level, individual wellbeing, skills and abilities are important to take into account. If the person with dementia is to feel confident and able to express their views, it is essential for the care professional or researcher to support them to develop and enhance

these. Some of the strategies and techniques employed in this study could be helpful, however it is essential to be flexible and cater to the needs and wants of individuals. In addition, psychosocial forms of support, such as counselling and support groups may help to promote confidence, wellbeing and coping ability (Bryden, 2002; Dyck, 2003; Bender & Constance, 2005; Cheston et al, 2003; Verkaik et al, 2005). Study findings revealed that with the onset and progression of dementia, individuals experienced feelings of depression, anxiety, vulnerability, fear, anger and shame as well as denial of difficulties.

The provision of emotional and practical support to relatives may also be important at the level of the individual, in order to maintain personal wellbeing (National Service Framework for Older People, 2001; Caring for Carers - the National Carers Strategy, 1999). The experience of dementia impacted immensely on relatives, as feelings of distress, guilt, shame, depression, isolation and loss of control were experienced and in addition denial of difficulties or avoidance of problems. These may have impinged on relatives' ability to empower themselves by asserting their views and rights and accessing the information and support they needed and they may also have impacted on the way they responded to and treated the person with dementia. Staff were not included in this study, but emotional support may also be necessary in order to maintain their wellbeing and to enable them to provide the best care possible. (Loveday, 1998).

(10.3.2) Organisational attitudes and practices

At the level of the organisation, it would be crucial for professionals to develop their own skills and knowledge, in order to support people with dementia to empower themselves. Knowledge of techniques to communicate effectively with people with dementia, and enhance self-confidence would be essential, as well as awareness of barriers to communication and empowerment and a commitment to and knowledge of strategies to overcome them. Recognising and focusing on the strengths and abilities which remain with the person and looking for ways to maximise these is also vital (Kitwood, 1995; Bell & McGregor, 2000; Gilliard, 2002). The findings show how people with dementia sometimes felt disempowered, particularly in residential services, which tended to cultivate dependency and overlook the abilities and skills of the person. It would be important for professionals to examine their behaviour and be aware of how this could impact either

positively or negatively on the person's quality of life and wellbeing. Revising negative attitudes and beliefs, such as the inevitability of decline, encourages professionals to consider ways of enabling the person with dementia to maintain their maximum potential. Conflicts may arise between safety and autonomy and it would be important to resolve these issues.

Other factors important to consider at this level include the structures within the organisation, for example, the rigid routines and procedures in residential services were disempowering for people with dementia. People were toileted at specific times only and there had to be a batch of people needing an optician or a dentist before they were called out, restricting choice and autonomy. A degree of flexibility may be needed and a willingness to take account of individual needs. Mirroring work carried out by Calkins (2005) and Judd et al (1998), the findings of the current study show that environmental factors can also impact on levels of empowerment and quality of care. The results reveal that smaller, familiar and appealing spaces are more empowering for people with dementia and can facilitate communication. Attending to these issues as well as the layout and type of furniture and seating arrangements may be important. The findings suggest that seating people in similar stages of dementia together may be beneficial.

In support of existing carers' policy, such as the Carers and Disabled Children's Act (2000), the results show that the provision of emotional and practical support to informal carers are necessary to maintain their wellbeing and quality of life, and enable them to care adequately for their relatives. The findings suggest that there is a need for organisations to develop a good understanding of dementia and the requirements of carers. In addition, information and support about services, dementia and caring for someone with dementia need to be made easily accessible.

Support for staff is also crucial. It is important for them to feel valued and empowered, as it is not easy to value and empower others if you do not feel valued and empowered yourself. Staff need appropriate training and support in order to provide the highest level of care (Little, 2005; Heid-Grubman, 2005). It is possible that inadequate levels of training contributed to the unsatisfactory aspects of care identified in some of the settings in this study. A greater emphasis on the psychosocial model of dementia in training may be

beneficial in residential services. In special day care centres, where staff had more training in person-centred approaches and communication skills, the level of quality of care was higher.

Apart from the provision of training, there are various other organisational issues which can impact upon quality of care. These include staffing levels, policies, procedures, job descriptions, induction procedures, supervision styles, quality assurance systems (Loveday, 1998) and also staff wellbeing which need to be taken in account (Kitwood, 1997; Hollinger-Smith & Ortigara, 2004). It has been argued that training for staff has little benefit, unless management is also committed to person-centred care and will work with staff to plan and implement it and provide support and feedback to staff. This may call for the revision of job descriptions, induction procedures and supervision styles. Managers need training and supervision in order to address these issues effectively and to be the 'enablers and facilitators.' Staff may need mentoring and on-the-job advice and managers must be prepared to offer emotional support to staff who are involving their own emotions in caring work, as well as guidance, constructive criticism and a role model to follow (Loveday, 1998).

(10.3.3) Maximising influence and control

At the service user power level, it would be important that individuals are provided with as much opportunity for involvement as possible. Wright's (1999) four-tier model of increasing involvement can be used to show how individuals could be involved at different stages. The first stage relates to providing adequate information, so that individuals know what is happening around them or to them and are able to make informed choices. As mentioned earlier and revealed by relatives, people with dementia themselves and staff, none of the individuals in this study were aware of their diagnosis. It had not been disclosed to them or they were in denial or had forgotten about it and consequently they sometimes felt confused and bewildered about what was happening to them. People with dementia were also disempowered in that decisions about their care and treatment were sometimes made by their relatives and professionals and although generally well intentioned it meant they had little involvement in decisions about themselves. Empowering practices at the first level may entail informing the person with dementia of

their diagnosis, the effects of the disease, the treatment options available to them and especially strategies which enable them to cope with the effects of the disorder. It is also essential to provide information in relation to future care and services, so they can choose what they would like. It would be important to present the information in a format that is easily understood (National Service Framework for Older People, 2001), which could involve using some of the techniques for communication with people with dementia discussed earlier.

The provision of adequate information to relatives and staff is also essential to enable them to feel empowered and care adequately (National Service Framework, 2001; National Carers Strategy – Caring about Carers, 1999). For example, it would be important that relatives are informed about their relative's welfare; that they and also formal carers are provided with information about dementia, issues surrounding caring for someone with dementia and support services, so they feel able to cope and provide care adequately.

Involvement at the second level entails gathering ideas or consulting individuals. The importance of consulting with and involving older people is highlighted in many policies, including the National Service Framework for Older People (2001) and the National Minimum Standards (2002 and 2003). In settings in this study, this may have involved eliciting the views and feelings of people with dementia about their environment and the services they were receiving. Additionally, finding out from them the degree to which they would like to participate in their care; consulting with them about whether they would like to walk or be wheeled around; asking for their opinions on food provided; and the activities they would like. Consulting and involving relatives is also important (National Service Framework for Older People, 2001). The input of relatives into care planning is invaluable, especially if the person with dementia is not able to provide detailed information themselves, as they have knowledge of the person's past life and interests, which if known and enacted upon could enhance the quality of life of individuals with dementia (Clarke, 1995). It is also vital to consult with relatives about their own care and support needs. The findings from this study suggest that relatives were under enormous pressures and they did not always receive the support they needed. Recent legislation (Carers and Disabled Children's act, 2000 and the Carers (Equal Opportunities) Act, 2004 combined policy) places a duty on the local authority to inform carers of their rights to an assessment of their

caring, work, educational and social needs and may help to address the problem. Staff were not included in this study, but it would also be important to confer with them about their training and support needs.

The third level relates to working with and involving individuals, such as inviting them to meetings and working groups; drawing on their expertise; and involving them in decision making and care evaluation. This did not happen in the services investigated in this study. As discussed in previous chapters, involvement of an empowering nature did not take place. The National Service Framework for Older People (2001) highlights the importance of the representation of older people across care services. It may be beneficial to invite people with dementia and perhaps also relatives and care staff to planning or management meetings and set up consultation forums in residential and day care services, with a view to developing services more appropriate for service users and their carers. For involvement to be empowering it would be important to ensure that service users' and carers' views are taken into account and make a difference. The fourth and last level entails supporting user led initiatives, where individuals may be encouraged to set up a support group for themselves, or participate in providing training or act as paid consultants. In the settings explored in this study, people with dementia or their relatives or even formal carers may have wished to set up their own support group or perhaps their own service discussion group. Comments, suggestions and requests could then be fed back to management and perhaps incorporated into the running of the service. Commitment to this level again involves willingness to take on board the perspectives and opinions of people with dementia and their carers, provide appropriate training and offer financial assistance if needed.

(10.3.4) Striving to include people with dementia and carers

At a societal-inclusion level, people with dementia and their carers should be treated as full citizens and have the same rights and opportunities as other people. These issues reflect aims of current legislation, which includes eradicating ageism (National Service Framework for Older People, 2001; The Employment Equality (Age) Regulations, 2006 - forthcoming legislation); enabling people with dementia and their carers to enjoy a high quality of life (National Minimum Standards for Care Homes; 2002; Carers Equal

Opportunities Act, 2004) and maximising their independence and control (Green Paper: Independence, wellbeing and Choice; 2005; NHS Plan, 2000). However, there may be a number of issues which need attention before this can happen. Some of these are discussed in brief below:

There are clearly huge problems with the funding of social care in the UK, which need to be addressed (Robinson, 2005; Liberal Democrats, 2002; Help the Aged, 2002). Financial constraints and a lack of resources may have contributed to the inadequate aspects of quality of care identified in this study and to the lack of carer support. As discussed in chapter two, older people are at a particular disadvantage, because local authorities often discriminate against them by allocating more money to younger people's services while neglecting those of older people (Kane, 2002; Little, 2005), although a recent policy 'Fair Access to Services,' (2002) aims to address this issue. People with dementia are most disadvantaged, as they are at the bottom of a hierarchy of ageism.

The problems highlighted may reflect a failure to implement legislation requiring that informal carers are adequately supported and involved and service users are enabled to participate in care planning and provision. Unfortunately, legislation does not always change people's behaviour (Sayce, 2000) and these policies have not been applied in general, but particularly to people with dementia. As mentioned, funding is an issue which needs to be addressed, but it has also been suggested that involving people with dementia presents a particular challenge to service providers because their views have been devalued through the stigma of both cognitive impairment and old age (Graham, 2003; Gillies, 1997). In addition, providing appropriate stimulation for people with dementia may present difficulties, because of a lack of training, communication difficulties and restrictive attitudes about what people with dementia can and cannot do. It is necessary to address issues such as stigma, inadequate training and communication problems at the level of the organisation, which prevent this legislation from being put into practice effectively.

As mentioned above, the lack of empowerment described could be partly explained by societal stigma. People with dementia bear a double stigma of mental illness and old age and prejudice towards these groups of people is still widespread in society (Madge, 2005; Kenny, 2001). Negative attitudes and behaviours towards people with dementia were

evident in this study. Sometimes individuals with dementia avoided contact with people with more advanced dementia, because they thought them to be 'funny' or 'odd' in the way they behaved or looked. Friends, family members and care staff also sometimes distanced themselves from the person with dementia and some of the disempowering practices described and observed may have been partly a result of staff perceiving individuals with dementia to be incapable.

Proposed suggestions and initiatives to address stigma include providing training and education for the public (Whitehead, 1999; Graham et al, 2003; Tryssenaar, 2003). Providing accurate information about dementia and addressing common misconceptions can help people to examine and change their attitudes about dementia and those about mental health and old age generally, reducing stigma. The media is an important socialising and educational agent which could help to reduce prejudice. It has been suggested that an effective way of changing people's attitudes is to encourage ongoing contact between service users and non-service users, preferably in a structured environment, such a work place setting (Sayce, 2000). Additionally Hughes (1995) has suggested several ways in which people working with older people can fight discrimination and promote empowerment. These include, recognising discrimination against older people and valuing individuals by appreciating their strengths and resources; listening to and involving older people and emphasising their personhood; recognising older individuals as people with equal status to others; and ensuring they have the same or better quality of life as other people. However, it has been argued that stigma is a societal issue, which needs to be addressed on a societal scale (Kenny, 2001) and that in order to make a significant difference, an overall, co-ordinated strategy is required, incorporating a multi-agency and multi-media approach across the country (Kaminski and Harty, 2000). It has been argued that political action is required and there is a need for laws and campaigns to stop discrimination and negative media portrayals of older people and people with mental illness (Bracken and Thomas, 2000).

Lastly, to maximise opportunities for empowerment, more advocacy schemes for people with dementia may be beneficial (Richards, 2005; Wright, 2005). There are few of these schemes for people with dementia in comparison to the number for other mental health and disability groups (Goodchild et al, 1999, Cheston et al, 2000). Organisations such as the

Alzheimer's Society and Age Concern have, until recently, mainly focused on carers' needs. Mental health organisations such as Mind, which has played an important role in empowering people with mental illness and still does, do not include people with dementia.

(10.4) Final Reflections

Having explored the findings and recommendations which can be made from them, the chapter concludes by reflecting on the strengths and weaknesses of the study and some of the challenges faced. Ideas for future research are also outlined.

(4.1) Strengths, challenges & limitations

Strengths

In keeping with the aims of the study, the methodology employed was successful in eliciting the views and feelings of people with dementia and their relatives. Much data were obtained, which generated some new and interesting findings. These are summarised in the table overleaf:

Summary of main findings from the study

- Triangulation of interview, video and observational data shows that it is feasible to elicit accurate information about services from people of a range of severity of dementia and therefore include them in service evaluation.
- The findings highlight a number of techniques to communicate effectively with people with dementia. These include, building a good rapport with individuals; using broader open-ended questions, pictures and scales; attending to non-verbal language; an ability and willingness to look for meanings behind narratives – see 4.5 and 10.1.1
- The results show, and identify a number of reasons to explain why, relatives' views about services are not always accurate and they do not always know how the person with dementia feels. They highlight the importance of consulting with the person with dementia themselves to find out how they feel.
- A wealth of information about dementia and services was generated from interviews with people with dementia and their relatives. The overwhelming losses experienced by people with dementia are notable, as well as the lack of communication and control in residential settings. Perceptions about day care services were more positive. Also significant is the finding that relatives felt disempowered by inadequate support and information in the community and in relation to their relative's care, as there was a lack of involvement and consultation.
- The study highlights a number of ways in which people with dementia and their carers can be empowered in research and in a more general sense – see 10.3.1-10.3.4.

Employing an ethnographic approach, which incorporated multiple methods, was beneficial for a number of reasons. It maximised communication and response; enabled a holistic picture of events to be gathered; and allowed accuracy of participants' comments to be tested, through triangulation of data. Although research was conducted solely within Jewish Care services, there is much which was learned which can be applied to non-Jewish services and people.

The process of research was empowering for participants, as their views were to make a difference to services. The findings were fed back to Jewish Care, with the understanding that they would incorporate these into their practices. It was intended that carer training packages would be developed, which should ultimately result in a better quality of care for people with dementia. In addition, potentially empowering data collection techniques were employed and in line with the ethos of empowerment, a number of personal benefits for participants involved in the research were identified, including increased self-esteem and opportunities to voice views and feelings. It was evident that some informants felt good about being involved and I would like to think they felt empowered, but cannot be sure.

Challenges

However, there were inevitably a number of challenges I faced during the course of the study. One of these was to maintain credibility and dependability throughout the research process. I was aware that my own beliefs and standpoint were likely to influence the results and I needed to minimise this effect. Ways in which this was achieved included taking in and recording all the available information; remaining open-minded throughout the research process and open to any unexpected results; and being careful not to impose meanings and interpretations on what was said or observed. Findings were shared with colleagues on a regular basis, who were able to offer alternative explanations and suggestions and data were interpreted as I went along, in case I needed to gather additional evidence and so that I could frame follow-up questions appropriately. In addition and in order to reduce the possibility of distortion, a small amount of quantification took place during analysis, that is, the number of people who felt a particular way or had a particular experience were counted and this information was tabulated (see appendices V-VIII). The video and observational data were cross-referenced with interview data to support the dependability of interpretation; checks were carried out with a second researcher to increase the reliability of observational data; efforts were made to minimise gaps in the video recording and cameras were placed where they would be least intrusive.

Another challenge I faced as a researcher was to maximise and support empowerment during the research process. I needed to develop my skills to facilitate communication;

support individuals to make the most of their abilities and skills; and enable them to have control over the research process, by for example, maintaining an equal relationship, working in partnership with and involving them as far as possible. This was not always straightforward. Developing appropriate methods and interview schedules took time, consideration and much research. Interviewing was sometimes stressful and required much patience and flexibility and there was a need to respond and adapt to the changing needs of individuals. Data interpretation was sometimes complex and time consuming. I needed to be able to effectively make links in words, look for meanings, listen carefully and so on.

Other challenges encountered included resolving multiple ethical issues, for example, in relation to obtaining consent and using a video camera – see 4.9. In addition, processes such as negotiating access to the different settings, meeting the needs and wants of individual staff, service users and relatives and as mentioned collecting data were sometimes complex. It was not always easy for me, for instance, to establish the most appropriate methods to use or prevent gaps in the video recordings, particularly if events were happening elsewhere, or access to the cameras was obstructed. Witnessing some of the not so good care practices in the care settings, while remaining a non-participant observer was emotionally draining and painful. I needed to be able to maintain a professional distance from events happening within the home and adopt a passive role, because any action or intervention would have distorted the data collected. This was not always easy to do.

Limitations

The project was carried out solely within the Jewish voluntary sector where social care services are better financed and resourced than many other care services across the country. Although I am not claiming the findings of the study are generalisable to other settings, there is evidence to suggest they may not be confined to Jewish Care (Train et al, 2005; Ballard, 2001). This study has identified some difficulties within dementia care settings, however further problems may be highlighted within other services.

The study aimed to be empowering for participants, an aim which was achieved to a certain extent. However there are additional possibilities, in that there was the potential for

participants to have had greater involvement in the research process, for instance, they could have been involved in formulating the research questions, in the development and selection of data collection techniques and so on. The methods employed reflect the state of knowledge at the time and were I to carry out a similar study in the future, I would endeavour to increase the level of participant involvement. There were also limits to the extent to which it was possible to empower some individuals, in terms of eliciting perspectives about services. In the residential homes, views and feelings about care services were obtained from 10 out of the 17 individuals. Perhaps views may have been obtainable from the remaining seven participants, with more time and perhaps with the use of different methods.

Another issue relates to the sampling technique employed. Participants were selected randomly, a requirement of the larger study to which this is attached. There are, however, limitations to this method of selection. For instance, people selected did not always know of their diagnosis, or they were in denial of problems they were experiencing, which slightly restricted the amount of information obtained about dementia. Selecting randomly also meant there was little control over the number of people in different stages of dementia in the sample. It appeared that individuals in residential services had more advanced dementia than those in day care centres, although this was a subjective observation, as measures of the severity of dementia were not taken or observed. The benefits of selecting more purposively include the possibilities of choosing people who were aware of and had come to terms with their diagnosis and the potentiality of selecting particular numbers of people in the different stages of dementia, which would have enabled me to address my research questions much more succinctly. Although difficulties may have been experienced, as for many participants, information about the stage of dementia was limited. Lastly, the scope of the study did not allow for the inclusion of care staff. Their views and perspectives may have contributed an additional and interesting dimension to the study and may have been helpful when making sense of the findings and exploring the results in depth.

(10.4.2) Issues for practice, policy and research

In contrast to past beliefs, results of this study show that eliciting accurate views and feelings from and thus empowering individuals in different stages of dementia is possible with humanity and appropriate techniques. The findings highlight the need to approach people with dementia themselves for their perspectives, as relatives may not always have a complete understanding of how people with dementia feel and may not have accurate knowledge about services. The results show that people with dementia and their relatives were disempowered at virtually every level of the empowerment model by the experience of dementia. In addition, although a number of aspects of quality of care were described to be satisfactory, individuals with dementia were disempowered by a lack of influence, control and social aspects of care in the residential homes and relatives by inadequate levels of support and information.

The results highlight a number of issues which warrant further consideration and exploration. There is generally a need for further research that incorporates the perspectives of people with dementia. The results of this study suggest that the views and feelings of people with dementia can be accurate and this is applicable to people of a range of severity of dementia. Including people with dementia in evaluation research could be useful when seeking to improve the quality of care and provide services responsive to individual needs. Further research, exploring service user perspectives on services outside the Jewish voluntary sector, may highlight additional problems to those identified in this study. The findings also indicate that it may be beneficial to look more closely at the effects of the physical environment, as analysis of data suggests this can impact significantly on the experiences of people with dementia. Lastly, the study included and highlighted the feelings and emotions of relatives and the lack of support received. However, findings also suggest that formal carers, particularly those in residential settings, are under a great deal of pressure and there is a need to examine further their experiences, perceptions, feelings and strategies for coping. It is important to address the needs of both formal and informal carers, since their wellbeing will inevitably impact on quality of care provided for the person with dementia.

Although it is likely that we will become much better at preventing and treating dementia, dementia is not an issue that is expected to disappear in the foreseeable future. On the contrary, as a result of the ageing population, the number of people with dementia is steadily increasing. We are going to continue to need health and social services for people with dementia and carers and we need to make further efforts to improve these, as they can have a significant impact on the quality of life of people with dementia and their carers. High quality services can be achieved in a number of ways, which include implementing relevant legislation; ensuring adequate financial commitment; providing training and support for staff; and carrying out evaluation research which includes, rather than eliminates people with dementia.

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APPENDICES

Appendix I

Interview questions for people with dementia in the residential phase of the project.

(Minor modifications were made to this schedule for the day care phase)

- **Life before the residential/Nursing home**

Tell me how it was for you before you came to live here

- **Life now at the residential/Nursing home**

And how does it feel for you being here now?

or

If you had a friend who was coming to live here, how would you describe it to them?/Lets imagine that someone you know well is coming to live here. Can you think of someone? Tell me about the person you are thinking of.

What would you say about how life is here?

Prompts (sometimes used)

- *Relationships*

What would you tell them about staff?

What about the other residents?

Do you see much of friends/relatives from outside? How is that?

- *Dignity*

Do you feel that staff treat you with dignity and respect, either in the way they address you or when providing personal care?

- *Choice*

Prompts:

-What would you tell them about the food?

-What do you like to eat?

- Is there anything you like but you don't get here?
- What would you say about the daily routine?
- How do you like spending your time?
- Do you have any ideas of things you would like to do here?
- Are there any things you don't like doing here?
- How do you feel about having your bath?
- Are there other things you would like to have/do at this time?
- What about times when you get up in the morning and go to bed at night
- Also the times that you eat ...
- How do you feel about these?

- *Independence*

Are there any things that you could and would like to do for yourself that you don't normally do?

- *Privacy*

Are there times that you feel you would like more privacy?

- *Physical Environment*

- What do you think about the way this place is decorated?
- What do you think about the colours?
- What about the chairs - are they comfortable?
- How about the noise levels?

- *Complaining*

How do you feel about telling staff if you don't like something or if something is wrong?

- **Health/Experience of dementia**

Can you describe what it's like for you to have dementia / Have you noticed any changes in your health? (*If unaware of diagnosis*)

- What things stand-out?
- How have they affected your life?
- How have they made you feel?
- How have you coped?

- **Other**

Is there anything else you'd like to say?

Appendix II

Interview questions for next of kin/relatives in residential phase

Slightly modified for the day care phase and depending on awareness or unawareness of diagnosis of dementia

- **Perception of relatives' problems**

Can you tell me, what are the main problems that your relative has? Why are they currently in the residential home?

- **Life before the residential/Nursing home**

Did you have the responsibility of caring for your relative before they moved into the residential home or if not did you have regular contact with them?

Can you describe what the situation was like at home?

-What sorts of support and/or information did you receive?

-How did you feel about these?

What was the best thing about them - and the worst thing?

-What services and information were actually available?

-Is there anything you think that could have been better? If yes what things?

-How was it do you think/what is your perception of how it was for your relative at home?

- **Experience of Alzheimer's**

Can you describe how your relative developing dementia has affected you/your life or other members of your family?

-What things stand out?

-How have they made you feel?

-How have you coped?

From your observations/ experiences/ perceptions how do you think developing dementia has affected your relative?

Communications

-Can you tell me how dementia has affected your relative's ability to communicate?

-Do they ever have difficulty talking to and understanding other people? In what ways?

-Do you ever find you have to alter your speech when you communicate with

your relative? How?

- Are there any ways in which you communicate with your relative other than verbally? If yes, how? Do you find that observing your relatives body language is useful when trying to understand how they feel or what they want? How?
- Do you ever find touch and physical contact is useful when communicating with your relative? If so how?
- How do you think communication difficulties that your relative may have make them feel?
- And how have they affected you?
- Has your relative's behaviour ever been challenging or difficult to handle? Can you give me an example? Why do you think they behaved like this? How did you handle it?

- **Life now at the residential/Nursing home**

Relatives' own perceptions

- How often do you get the opportunity to visit your relative in the residential home?
- What do you think/how do you feel about the care that your relative is currently receiving in the residential/nursing home? (eg, staff, food, activities, personal care, physical environment).
- Why was Jewish Care chosen? Why this particular home?
- How much involvement do you and your relative have in the planning of care?
- What kinds of support you do receive now?
- Is there any support you feel you need, other than that which you are receiving? If yes, what kinds of support?

Relatives' perceptions of how people with dementia feel

I would like to ask you now, how you think your relative feels about this home and the care that they are receiving. That is, from your observations when you've visited and from spending time with /talking to your relative.

Relationships

How do you think they feel about:

-Staff – do you think they have better relationships with some staff than others.
Why?

-Other residents here

-People visiting (friends/relatives)

Choice

What about:

-Food

-Routine – times: getting up, going to bed, eating...

-Personal Care – bathing, dressing, toileting

-Leisure/activities

Independence

Is there anything you/they feel they could and would like to do for themselves that they currently don't do?

Physical Environment

How do you think they feel about :

-The decoration

-The colours

-What about the chairs etc

How much say does your relative/you have in such issues?

Has your relative mentioned to you anything they don't like/would like to change about the care that they receive?

Is there anything you think that could be better?

What is the worst thing about this home?

How do you or your relative feel about complaining if you don't like something or if something is wrong?

Has your relative mentioned anything to you/have you observed anything that they particularly like about this home?

What to you are the best things about this home?

- **Other**

Is there anything else you'd like to say?

Appendix III

Table 1: <i>Main themes for people with dementia</i>
Life before the home or at home
Life at the residential home, day care centre or individual's home
Relationships (with staff, other residents/members & visitors)
Dignity
Choice
Independence
Privacy
Physical Environment
How people felt about complaining
Health, experiences of dementia and coping

Table 2: <i>Main themes for relatives</i>
Situation/Life at home
Affects of dementia on themselves & on their relatives
Coping
Information and support received
Views about residential/day care/home care
Involvement in care/reviews
Frequency of visits
How does their relative perceive care received (sub-themes - same as those listed in table 1)

Appendix IV

Table 3: Ethics protocol: Stated standards and proposed actions

Anticipated issues and the context in which they may arise	Proposed action by the team
<p><u>Sharing of information</u></p> <p>1)The need for openness and communication with all participants.</p> <p>2)To engage staff and service users throughout the research project and alleviate any personal anxieties about the rationale and purpose of the study.</p> <p>3)The need to provide knowledge of the project which is the same and equal for everyone.</p> <p>4)Interim requests for information – e.g. from interested parties such as Jewish Care or Middlesex University.</p>	<p>1)In all stages of the project we will seek approval and advice and where possible we will encourage participants to make their own choices in assisting us with our enquiries.</p> <p>2) A Steering Committee and a Joint Research Committee have been formed incorporating staff and user representatives. These representatives will have a dual role of disseminating information regarding the project and feeding back any comments or concerns from staff and service users.</p> <p>3)Invitations to meetings between staff and the research team will be circulated at intervals during the project to provide updates and to receive feedback from staff. Interim newsletters will also be circulated to staff and service users.</p> <p>Unless the requests are within the agreed exchanges regarding the flow of communication and continuance of partnership, the research team will not release any information about individuals, circumstances or findings until such time and place seen as appropriate and relevant to their tasks.</p>

Wellbeing of people with dementia participating

1)The interviews may highlight communicative impairments and thereby lead to frustration or distress.

2) The nature/content of the questions or the manner of the interview may prove distressing.

3)The use of remote microphones attached to residents may prove an irritant

1) Throughout the interview process the wellbeing of interviewees will be monitored. Signs of anxiety or distress will lead to the postponement of the interview. Following liason with care staff, a second attempt to interview may take place – if anxiety persists the interview will be terminated.

2) Interview schedules have been designed to be as simple and non-threatening as possible. The interview will include repeated prompts for the interviewee, reminding them that they may pass on any question or terminate the interview if desired. Copies of the interview have been circulated to next of kin for information and to address any concerns regarding the content and nature of the interviews.

3)A research team member will be present in the home throughout the period of recording. If microphones prove an irritant their use will be postponed. If, after liason with care staff and further attempts at attachment, irritation persists, the use of the microphone will be ended, but alternative options will be considered – e.g. attaching the microphone close to, but not on the participant.

<p><u>Privacy of participants</u></p> <p>1) The usage of video cameras may infringe upon the privacy of project participants</p>	<p>1) Cameras will only be placed in communal areas in the home; no filming will be take place in private areas in care homes. The siting of cameras will be undertaken with the full knowledge of care staff and service users and following liason with the head of home. Care staff, and service users will be informed of the right to switch off the camera under circumstances in which they deem filming appropriate. Follow-up interview will attempt to elicit an explanation of the reason(s) for switching off. If a refusal to give reasons is evident, no further prompting will ensue.</p>
<p><u>Confidentiality</u></p> <p>1) Access to data generated throughout the project, particularly for audio and visual.</p> <p>2) Usage of data following completion of project</p> <p>3) Grounds on which code of confidentiality may be superseded – abuse.</p>	<p>1) The staff, service users and their next of kin have all been given a written guarantee that only members of the research team will have access to the data generated by the project.</p> <p>2) Following the completion of the analysis stage of the project all data elicited during fieldwork will be destroyed. Publication of materials or their use for training purposes will protect anonymity but where individuals or settings may be recognised, permission will be sought prior to presentation.</p> <p>3) During the fieldwork or analysis stages of the project any act, gesture, or verbal exchange deemed by the research team to constitute abuse will be acted upon by the team. The incident, and any associated evidence, will be handed to Jewish Care management, to be dealt with in accordance with their stated policy on abuse and anti-discrimination practice. All participants offering their consent are clear about this policy on ethics.</p>

<p><u>Implications for staff, service users and relatives not selected for the project</u></p> <p>1) Those not selected for the project may be caught on camera during the fieldwork stage.</p> <p>2) Non-participants may forget, be unaware or have concerns regarding the project and its intentions</p>	<p>1) The equipment purchased for the project includes a facility for pixelating the faces of any non-participants caught on camera during filming</p> <p>2a) Posters will be strategically placed throughout each care home and day centre to inform and remind staff, service users and visitors of the project and provide contact details should they wish to raise any questions or concerns.</p> <p>2b) Talks have been given to the entire staff group of two homes where non-participant staff expressed a need to discuss the project with the team.</p>
<p><u>Cultural awareness and sensitivity</u></p> <p>1) Research may risk infringing upon the cultural practices of this exclusively Jewish organisation.</p> <p>2) Misinterpretation of cross-cultural actions and behaviour</p>	<p>1) Training of research team in Jewish calendar and culture. Liason with Heads of Homes and Day Centres regarding timing of filming and other data gathering procedures</p> <p>2) Inclusion of staff representatives in all stages of the research project – including the analysis of data. Their contributions to be included in the findings.</p>
<p><u>Whose side are we on?</u></p> <p>1) In the event of an internal dispute within a care home or similar establishment.</p> <p>2) Blaming the researcher – e.g. with regard to behaviour, poor performance, aggression in residents</p>	<p>1) The research team will not entertain information nor will they act as witnesses to any industrial dispute, differences of opinion or any other direct or indirect disputes of a personal, interpersonal or inter-group nature between employees, service users and employer/organisation.</p> <p>2) Where such incidents, comments or observations are made, they will be noted in a 'diary of events' which will be included in any interpretation or findings. However such events (unless the research team deem otherwise) will not constitute a reason for terminating or interrupting the gathering of data.</p>

Example of information sheet used (adapted according to phase of the project and participant)

INFORMATION LETTER

[A research grant from the Community Fund]

Jewish Care and research staff from Middlesex University have successfully applied for and received a research grant from the National Lottery Charities Board. This will finance the costs of a three-year intensive study of communication between people with dementia of the Alzheimer's type and their carers.

The research team (Richard Ward, Neeru Aggarwal, Henry Minardi, Professor Tony Vass, who is the Director of the project, Beau Cybyk and Cydonie Garfield) will consider three settings (residential, day and home care) within Jewish Care. The project will encompass interactions and communications between care staff and family carers (including volunteers and family members); care staff and family carers with clients; and clients with clients.

Building on current understanding and expertise throughout Jewish Care, the research project aims to increase knowledge of the needs of people with Alzheimer's and how carers may best respond to those needs. The research team is confident that much can be learned from the findings of this project to enable carers to deliver better support and a more rewarding experience to people with Alzheimer's. At the same time, the findings can shed light on how people experience Alzheimer's and attempt to cope with its effects.

In order to capture as many of the different aspects of communication as possible, a combination of research methods will be used to collect information. These will include questionnaires, tape recorded interviews, observation and examining documents. The team will also use video cameras to record contacts between people with Alzheimer's and their carers.

The research project has three phases. Phase I will look at residential care; phase II will consider day care and phase III home care. It is expected that completion of all three phases should take between 12 and 15 months. At present the research team is in the process of preparing for phase II which is expected to commence within the next two to three months. A major aspect of the preparatory work is to seek consent from a random sample of people with Alzheimer's and their carers.

The project is guarded by a strict code of ethics and conduct which will require all participants to respect each other's position and practice in the organisation and confidentiality of material. There is a guarantee that no insider or outsider will have access to the research material other than the research team. Any publications arising from the research (reports, books, papers, training packages etc.) will protect participants' anonymity and where there is a need for reference to be made, the names of both settings and individuals will be changed. It is intended that for those selected to be involved in the project, a consent form (giving clear information about the purpose of the project, code of conduct and ethical issues) will have to be signed and countersigned by participants and the Director of the project.

Example of consent form used (adapted according to phase of the project and participant)

RESEARCH STUDY:

**COMMUNICATION PATTERNS AND THEIR CONSEQUENCES FOR EFFECTIVE CARE.
(Supported by a research grant from the Community Fund)**

CONSENT FORM

- | | | |
|----|---|--------|
| 1. | Have you read the information sheet, or has anyone discussed this research project with you? | YES/NO |
| 2. | Have you had the opportunity to ask questions and discuss this project? | YES/NO |
| 3. | Have you received satisfactory answers to your questions? | YES/NO |
| 4. | Have you received enough information about this project? | YES/NO |
| 5. | An integral part of this research project is the use of video and audio recording. Do you agree to participate in these recordings. | YES/NO |

- Your participation in the project is entirely voluntary. You are free to decline to enter or to withdraw from it at any time without having to give a reason. If you choose not to enter the study, or withdraw once entered, this will in no way affect your employment.

Having read and understood the above, I agree to take part in this project.

Participant's signature

Date

Name (in block capitals)

Guardian's/Next of Kin's signature (if appropriate).....

Date.....

Name (in block capitals).....

Project Director or his representative's signature

Date

N/R/consent/pwd

Appendix V

Table 4: Views of people with dementia about home and care received

Theme	Satisfied/ Happy	Dissatisfied /Unhappy
Home	2	5
Levels of choice/independence	0	6
Levels of activity	0	9
Levels of contact with others	0	6
Privacy	4	0
Physical environment	7	0
Feelings about complaining	2	5

Table 5: Relatives' perceptions of how people with dementia view the care received

Theme	Satisfied/ Happy	Dissatisfied / unhappy	No views *	Did not know
Life at home	16	2	0	0
Levels of choice/independence	5	1	4	7
Levels of activity	4	2	3	10
Levels of contact with others	6	2	3	7
Physical environment	3	0	3	12
Relatives' own perceptions of residential care				
Care received	15	2	0	1

* Thought relative held no views, because of limited awareness of what was happening around them

Appendix VI

Table 6: Views of members about day care centres

Theme	Satisfied/ Happy	Dissatisfied/ Unhappy
Day centre	9	0
Levels of choice/independence	5	0
Levels of activity	5	0
Levels of contact with others	7	0
Physical Environment	6	0
Feelings about complaining	5	1

Table 7: Relatives' perceptions of how people with dementia viewed day care received

Theme	Satisfied/ Happy	Unsatisfied/ Unhappy	Did not know
Life at day centre	9	1	0
Levels of choice/independence	1	0	9
Levels of activity	3	0	7
Levels of contact with others	1	0	9
Physical environment	0	0	10
Relatives' own perceptions of day care			
Care received	8	1	1

Appendix VII

Table 8: Experiences of people with dementia of their illness, as indicated by people with dementia and their relatives

Experience	Number of people (out of 27)	Percentage of People
Loss of independence	27	100
Memory loss	27	100
Communication difficulty	26	96
Frustration/Anger	15	56
Sadness/Depression	15	56
Confusion/ Bewilderment	8	30
Needing attention	6	22
Loss of self esteem/ self confidence	4	15
Obsessive behaviour	4	15
Feelings of aggression	3	11
Fear	3	11

Table 9: Coping strategies employed by people with dementia, as indicated by people with dementia and their relatives

Coping Mechanisms	Number of people	Percentage of people
Coping - Covering up	11	41
Coping – Getting on with things/ actively involved	7	26
Coping – Using memory aids	6	22
Coping - Withdrawal	6	22
Coping – Denial	3	11
Coping – Humour	2	7

Appendix VIII

Table 10: *Relatives' experiences of dementia and support received*

	Number	Percentage
Psychological pressures	27	96
Physical pressures	23	82
People requiring information/support	19	68
Those satisfied with levels of information/support received	4	14