“That’s how we do it... we treat them all the same”
“That’s how we do it…we treat them all the same”: An Exploration of the Experiences of Patients, Lay Carers and Health and Social Care Staff of the Care Received by Older People with Dementia in Acute Hospital Settings

By

Fiona Cowdell
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INTRODUCTION

‘That’s how we do it … we treat them all the same’

This study aimed to explore the experiences of patients, lay carers and health and social care staff of care received by older people with dementia in the acute hospital setting. In view of the ageing population, an increasing prevalence of dementia and the emerging dignity agenda this is a particularly topical subject.

Four elements are included in this book: a literature review, a research study, a practice development project and an integrative review. A literature review sets person-focused research in the context of dementia research as a whole. It also identifies ways in which studies have been conducted in an ethical and meaningful manner.

An ethnographic approach was used in the research study to collect data through observation, conversations and interviews. Findings portray a bleak picture of the care of this vulnerable group. Patients demonstrated, through words and actions, how difficult they found the experience. Lack of communication was an issue as was the obvious distress caused by delivery of personal care. Lay carers were relatively uncritical although this may have been due, in part, to the recruitment process. Staff generally appeared to have good intention. Most stated that they had received little or no preparation or education in dementia care. Many staff functioned almost entirely within the “bed and body” framework. They frequently avoided communication with patients. Staff worked in a deeply embedded habitus, in which they appeared not to really think about what they were doing. They demonstrated a lack of empathy with patients.

The concept that staff were working in a “switched off” mode and lacked empathy called for a practice development project that engaged them on both cognitive and emotional levels. A practice development project based on the philosophies of confluent education and situated learning was implemented. Initial evaluation has demonstrated some tangible changes in practice.

An integrative review draws these elements together into a coherent whole. Potential contributions to the body of knowledge are acknowledged, as are limitations of the work. This study has shown that people with dementia, even those at an advanced stage and with superimposed physical
illness, can be engaged in research that is both ethical and meaningful. It has shown that improvements in practice are possible. They need to be underpinned by a belief in the personhood of staff as well as patients. Areas for further research and practice development in this vital subject have been identified.
CHAPTER ONE

LITERATURE REVIEW

Introduction

It is well recognised that the prevalence of dementia in older adults is increasing (Alzheimer’s Society 2006). Having worked as a registered nurse in acute hospitals for many years I was aware that some of the care provided for older people with dementia was good and some less so. As the number of people with dementia requiring acute care is ever increasing I felt it was vital to investigate current care and consider much needed developments.

The increase in dementia is reflected by a huge rise in the amount of research into this area. This review addresses the question: is it possible to engage people with dementia in research in a way that is both ethical and meaningful? Three distinct phases in this chapter attempt to answer this question.

Phase one sets person-focused research within the context of dementia research as a whole. This phase considers cumulative reviews of dementia research including systematic reviews, meta-synthesis, meta-analysis, re-analysis and literature reviews. Eight hundred and sixteen papers were identified that met the inclusion criteria. The subject of each of these studies was identified and subjects clustered into ten categories: investigation of disease process, medication, treatment non-pharmacological, diagnostics and assessment, activities of life, care givers, person focused, culture specific, ethics and law and cost. Diagrammatic representation of the categories demonstrates the directions in which dementia research has moved over the last three decades. By far the most work has followed the biomedical model concentrating on investigation of the disease process and the use of medication. There has been a steady rise in studies about the ethics of dementia care, non-pharmacological treatments and techniques for diagnosis and assessment. It is evident that in more recent years there has been a small, but growing, interest in person-focused research studies that seek to understand the experiences and views of people with dementia. Phase one sets person-focused dementia research within the
broad landscape of dementia research. Phase two provides an overview of published studies that include people with dementia; forty-five papers met the inclusion criteria. These studies are assessed against a set of criteria that have been developed from existing models for evaluating qualitative research and adapted specifically for use with research involving people with dementia. Studies have been ranked as levels one, two or three according to how closely they met the criteria. Three studies were ranked at level one, meeting the criteria most closely; thirty seven were at level two and five at level three. All studies provided some evidence that it is possible to involve people with dementia in research in a way that is both ethical and meaningful, although the quality of involvement was extremely variable. Reflection on the allocation of studies into the three levels suggested that the way in which decisions had been made was not entirely transparent. It was considered that using a detailed set of criteria may have detracted from reviewing studies from a holistic perspective. This idea generated phase three of the review.

Phase three reconsiders the studies that were categorised at level one. The signal from each of these papers was high. That is, they all appeared to provide an exceptionally valuable contribution to answering a question. However this value was not necessarily fully explicated when using the phase two criteria. The three studies were reviewed again using the fundamental concepts of qualitative research methods and, in particular, the narrative approach. This second analysis allowed a more global review that enabled interpretation beyond that previously achieved and clearly demonstrated the aspects of these papers that identify them as being at the forefront of ethical and meaningful research involving people with dementia.

**Background**

Dementia is defined by the World Health Organisation as “a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is a disturbance of multiple higher cortex functions including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgment. Consciousness is not impaired” (WHO 1992). The Alzheimer’s Society (2003) defines dementia as a “group of symptoms caused by the physical impact of disease or injury on the brain”. It is stated that each person will experience it in their own individual way but that most will live through a decline in memory, reasoning and communication skills together with a gradual loss of the skills needed to carry out daily activities.
There are a range of different types of dementia. An estimate of the proportions of people with the different forms of dementia is provided by the Alzheimer’s Society (2003). These are: Alzheimer’s disease 55%, vascular dementia 20%, dementia with Lewy bodies 15%, fronto-temporal dementia 5% and other dementia 5%.

Diagnosing dementia is not a simple procedure, however early diagnosis is becoming increasingly important as drug therapies for treating different conditions are becoming available. It is also vital in helping the person to plan their future and the early identification of sources of advice and support (Alzheimer’s Society 2003). Diagnosis is usually made by excluding other causes of symptoms. Investigations include physical examination, blood tests, computerised tomography or magnetic resonance imaging scans and comprehensive memory testing using one or more validated assessment tools (Brown and Hillam 2004). It is noted that dementia is a complex syndrome to diagnose accurately and it may be that a definite diagnosis is only established after death at post mortem or, in very rare cases, through brain biopsy.

A number of authors have challenged the notion that dementia is wholly a physical disease. Kitwood (1997a) suggests that it is a combination of physical factors and societal attitudes and treatments. Kitwood describes a “new culture” of dementia care in which he suggests that there is a need to move from the traditional view of dementia as a devastating disease of the central nervous system which results in progressive destruction of personality and identity. He argues convincingly that in order to provide high quality care it is necessary to change thinking about dementia towards a view that dementing illness is a form of disability in which care received by the person is crucial to the way in which they are affected by the dementia. Bartlett (2000) investigated the concept of dementia as a disability and suggests that Kitwood’s seminal work has enabled a move from thinking about the “dementia sufferer” to a broader view in which the person with dementia is acknowledged to be a person not only with cognitive impairment but also with a variety of social restrictions and barriers.

Kitwood’s (1997a) work about dementia care has parallels with the gradual involvement of people with dementia in research. For many years it has been assumed that this group are unable to participate in research and cannot share their views and experiences. It is suggested by Wilkinson (2002) that this attitude does much to reinforce negative stereotypes of this disability. Over the last two decades there has been an increasing call for greater inclusivity in research (for example Cotrell and Schulz 1993, Downs 1997). Such a move has been slow to develop, although there is an
increasing body of literature that examines ways in which people with dementia can be included in research. Wilkinson (2002), Barnett (2000) and Sabat (2001) have been particularly influential in this field.

Dementia is acknowledged as being a major issue in the health and social care agenda. Prevalence of dementia is gradually increasing as the population ages. It is estimated that dementia currently effects over 700,000 people in the United Kingdom and that by 2010 this number will have risen to 840,000 (Alzheimer’s Society 2006). There is, therefore, a clear need to continue research work into dementia from a variety of perspectives.

Phase One

Phase one provides an overview of dementia research and sets person-focused studies within a wider context. The history of dementia research is long and varied. An extensive review of the literature suggests that McLean’s (1987) assertion is accurate in that, for the first half of the twentieth century, mental decline in the elderly generated little interest with cognitive failure being dismissed as an inevitable part of ageing.

A literature search was completed with the objective of identifying the scope and direction of dementia research. In view of the exceptional volume of work on this subject, only review papers were considered. This process produced a trajectory of research over a fixed time period. Databases searched included: Cochrane database of systematic reviews, AMED 1985-12/2004, PsychINFO 1887-12/2004, Medline 1951-12/2004, BNI 1994-12/2004, ASSIA, eLSC and CINAHL 1982-12/2004. Search terms used were dementia, Alzheimer$, literature review, systematic review, meta-analysis, meta-synthesis and re-analysis. Selection criteria were that publications were journal articles, written in the English language, with dementia or Alzheimer$ in the title and have literature review, systematic review, meta-analysis, meta-synthesis or re-analysis as the major descriptor in either the abstract or database information. Studies primarily concerned with people under the age of sixty five were excluded.

It is acknowledged that this strategy would not yield every possible review of dementia research. A total of eight hundred and sixteen papers met the selection criteria. Papers were reviewed and forty one subjects were identified. Subjects were clustered into ten broad categories as shown in table 1-1. A small number of papers included information that could have been categorised in more than one way. In these cases the major subject was identified and used for categorisation.
<table>
<thead>
<tr>
<th>Category</th>
<th>Subjects Included</th>
</tr>
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<tbody>
<tr>
<td>Investigation of disease process</td>
<td>Genetics, epidemiology, risk factors, prevention, prediction, reversibility, screening, studies of specific symptoms</td>
</tr>
<tr>
<td>Medication</td>
<td>Anti-dementia drugs, other types of medication used for treatment of symptoms of dementia</td>
</tr>
<tr>
<td>Treatment non-pharmacological</td>
<td>Reality orientation, validation therapy, Snoezelen, psychosocial interventions, complementary therapies, rehabilitation, behavioural interventions</td>
</tr>
<tr>
<td>Diagnostics / assessment</td>
<td>Imaging, biochemical tests, biological markers, assessment techniques used in practice</td>
</tr>
<tr>
<td>Activities of life</td>
<td>Respite care, nursing homes, feeding, falls, disclosure of diagnosis, awareness of dementia, nursing roles, environment, pain, sexuality</td>
</tr>
<tr>
<td>Care givers</td>
<td>Psychosocial interventions for carers, carer strain, effect of respite care on carers</td>
</tr>
<tr>
<td>Person focused</td>
<td>Active involvement of people with dementia in care and research process</td>
</tr>
<tr>
<td>Culture specific</td>
<td>Named cultures, nationalities, prisoners</td>
</tr>
<tr>
<td>Ethics and law</td>
<td>Ethical and legal considerations in dementia care and research</td>
</tr>
<tr>
<td>Cost</td>
<td>Care, medications</td>
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</tbody>
</table>

Table 1-1: Categories of dementia research

The number of studies in each category was identified and is presented as a graph (figure 1-1).
Phase one demonstrates clearly how quickly dementia research has developed with the most dramatic rise being in the last decade. This may have been influenced by recognition that the prevalence of dementia is increasing rapidly as the population ages. It has highlighted an ever more urgent need to find ways not only to prevent or cure dementia but also to develop ways in which quality of life for people with dementia can be enhanced.

Greatest areas of growth have been investigation of the disease process and development and use of medication. There is undoubtedly a need to continue biomedical studies that aim to provide a better understanding of the disease process and therefore potential for identifying cause and possibly cure. Research into the use of medication for management of symptoms has continued. However the increase of studies into medication can mainly be attributed to the development in the mid 1990’s of anti-dementia drugs that offer some new hope of slowing disease progression.

Whilst biomedical research remains vital, it is equally important that other aspects of dementia research are nurtured to ensure a more holistic picture of the possibilities of dementia care. An increase in studies about the ethics of dementia care and research is noted. This remains an area of much debate for health and social care workers and new thoughts on this aspect of care are being continually generated. There has been a steady rise in studies into non-pharmacological treatments. It can be argued that
the move towards more person-centred strategies has been influenced by approaches such as reality orientation, validation therapy, resolution therapy and reminiscence, which have gradually evolved from the 1950’s onwards (Kitwood 1997a).

Identification of person focused reviews reveals very clearly that this is a minority area in dementia research at present. The review identified five papers that met the selection criteria; one published in 1996, one in 1997, two in 2002 and one in 2004. Each of these reviews cited a relatively small number of references. Although these papers have been categorised as person-focused their thrust appears to be to provide evidence of a lack of consistent, high quality research that genuinely engages people with dementia. Despite the fact that person-focused dementia research remains comparatively rare, these papers do indicate that there is a growing interest in this field. These papers are briefly reviewed.

In a broadly person-focused literature review, Keady (1996) covers a range of issues concerning dementia care and research in relation to the early experience of dementia and revealing of diagnosis. Keady also considers the impact of dementia on carers and the service demands that it generates. It is noted that much social research has considered the impact of dementia on care givers rather than the person with dementia. Keady (1996) comments that there are a small but increasing number of studies that directly seek the views of people with dementia. Whilst endorsing this growth, he cautions against the tendency to conduct research with people with early stage dementia to the detriment of those with more advanced disease.

An examination of literature relating to three aspects of the person with dementia: a person’s sense of self, an individual’s rights and the value of seeking the perspectives of the person with dementia was undertaken by Downs (1997). This author provides a concise overview of some of the key work in her consideration of the emergence of the person with dementia in research. She notes that to date the medical model has dominated in this area and even when people with dementia have been involved it has tended to be those in the early stages of the disease that have been included. Downs concludes that current literature increasingly gives value and importance to the person with dementia. She indicates a need to move towards an emphasis on the individual and a distancing from the language of victims and suffering and also suggests that there is a need to embrace people with more severe dementia in the research process.

Nolan et al (2002) take up the issue of involving the person with dementia. Drawing on a wide range of recent literature from health and social care domains these authors identify common themes in dementia
care and research. They note that over the last twenty years carer research has been far more in evidence than that which directly involves people with dementia. They identify the paradox that, despite comprehensive literature on this subject, there remains little evidence of the effectiveness of current approaches to care and support. Nolan et al (2002) recognise that there is an aspiration towards including people with dementia in service development and research but that, in reality, the views of this group are rarely sought (Zarit et al 1999, Moriarity and Webb 1997) or may be ignored (Gwyther 1999). Nolan et al (2002) state that there is a need to develop models of research and practice that are more inclusive and empowering and which acknowledge the person with dementia as being “experts in their own experience” (Reid et al 2001). Nolan et al (2002) advocate equality between the person with dementia and the researcher as being a way of promoting effective investigation. They advocate the use of an “exchange” model rather than the more commonly used procedure driven or questioning approach (Qureshi et al 2000).

Ways in which research with people with dementia can be enabled are also considered by Dewing (2002) who critically reviews literature around a competency based approach to informed consent. She argues that a simple extension of this model is not an adequate strategy for people with dementia and may lead to exclusionary ethics. Dewing (2002) describes her work on a theoretical foundation of consent for people with dementia and proposes a model for consent. Dewing (2002:157) suggests that there is a need to adopt a “revisionist, person-centred, inclusionary approach to consent”, and goes on to cogently justify and explain this approach.

Traynor et al (2004) discuss inclusion in relation to evaluating effectiveness of drug treatments for dementia. In an extensive literature review, the method of which is clearly described, these authors note the paucity of user involvement in this type of evaluation. Although they acknowledge the constraints placed on researchers, for example the European Agency for the Evaluation of Medicinal Products (1997) defines the areas in which clinical trials of drugs used in the treatment of dementia should provide evidence, they continue to argue convincingly that there is also a need to investigate aspects of quality of life that are important to patients rather than relying wholly on medically defined outcomes.

These reviews offer an insight into the current state of research involving people with dementia. Whilst they view the subject from differing perspectives it can be argued that there are similarities in the key messages that they convey. Keady (1996) and Downs (1997) acknowledge that far more attention has been paid to carers than to people with dementia and that, when people with dementia have been involved in
research, it has tended to be those in the earlier stages of the disease process. Nolan et al (2002), Dewing (2002) and Traynor et al (2004) also indicate a lack of involvement. However, the thrust of their arguments appears to be that there is a need to develop new and innovative ways of researching with this group rather than trying to fit approaches to these studies into existing moulds.

It is likely that the gradual emergence of person-focused research has been influenced by a number of factors. A trend towards including service users and carers in research, particularly in health and social care, started in the early 1990s with Government initiatives such as The Health of the Nation (Department of Health 1992). The inclusionary message is clearly restated in more recent documents, for example Patient and Public Involvement in the new NHS (Department of Health 1999b), The NHS Plan (Department of Health 2000) and the National Service Framework for Older People (Department of Health 2001b).

In addition to societal changes there is a gradual but growing movement that supports people with dementia being actively included in research. It is eloquently argued by Bond and Corner (2001) that to understand the meaning of dementia it is vital that we gain the perspectives of people with the condition. These authors are clear that any research must be designed to ensure that the integrity of an individual’s personhood is maintained. One powerful proponent of the active involvement of people with dementia is Wilkinson (2002) who, in an innovative text, sets out how such an aim can be achieved. This work is gradually being elaborated on by a range of writers who have considered specific issues in involving people with dementia in research. Examples of these include ethical issues that have been explored by Bartlett and Martin (2002); ways in which user views can be integrated into the evaluation of drug therapies by Traynor et al (2004) and Gibson et al (2004); methods of managing consent by Hubbard et al (2002); the use of focus groups by Bamford and Bruce (2002) and ways in which video recordings can be incorporated into research with people with dementia (Cook 2002). The move towards including people with dementia in research is primarily being driven in the social research arena. There are hints that this approach may be embraced, to some extent, by more traditionally biomedical investigators. For example, one person-focused study has been undertaken by a medical practitioner (Marzanski 2000). There is, to date, little evidence of further person-focused research by medical practitioners.
Phase Two

Phase two involved a literature search for studies that sought the views of people with dementia. In view of the relative scarcity of studies, the search did not follow the precise and linear approach that is advocated for quantitative systematic reviews (Centre for Reviews and Dissemination 2001). A more pragmatic approach was taken. Although the approach is unorthodox, it is transparent, and that is an attribute that Walsh and Downe (2005) consider vital to the integrity of a review. A vast number of studies initially met the search criteria and were judged to be “hits”. However, on review of title followed by abstract many were eliminated as they were not relevant. Details of this stage of the search are provided in table 1-2.

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<thead>
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<th>Number rejected at title</th>
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<td>6119</td>
<td>6095</td>
<td>6</td>
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<td>BNI</td>
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<td>AMED</td>
<td>8</td>
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<tr>
<td>MEDLINE</td>
<td>143</td>
<td>135</td>
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<td>7</td>
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<tr>
<td>PSYCHINFO</td>
<td>41</td>
<td>39</td>
<td>0</td>
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<td>6367</td>
<td>6329</td>
<td>7</td>
<td>31</td>
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</table>

Table 1-2: Phase two literature search

A broad based search strategy was used; this could have been refined. However a low success rate in finding relevant studies is perhaps an additional indication that research involving people with dementia remains far from mainstream. Location of relevant studies was problematic in that many studies that appeared suitable at title, or even at abstract, were found to be guidance on how to undertake research with this group rather than completed studies. Those studies rejected at title or abstract clearly did not involve people with dementia.

Full studies considered included thirty-one from established databases supplemented by a more fruitful search of the Electronic Library for Social Care database, the grey literature, a hand search of Dementia: The International Journal of Social Research and Practice with a subsequent search of reference lists of articles that met the inclusion criteria. Articles were rejected at this stage for one of three reasons: if they included the experiences of people with dementia only as an adjunct to the views of others; if they had a major focus on quantitative methods and used
Literature Review

qualitative approaches as a secondary method and, finally, if papers were summary reports that did not contain sufficient information to allow them to be assessed. It is acknowledged that application of these exclusion criteria is largely based on the subjective opinion of the researcher and that this will have influenced the selection of studies reviewed. A number of promising studies are unpublished and unavailable. It is acknowledged that this review is not exhaustive. However, it does offer an insight into the progress to date on research in this specialist field.

A total of forty-five studies were identified for full review. These studies do not lend themselves to a traditional systematic review methodology which, as Booth (2001) notes, suffers from the characteristics of “institutionalised quantitavism”. The non-conventional approach taken for this phase of the review has been influenced by the concept that attempting to imitate quantitative review methods with qualitative studies may compromise much of the progress that has been made in developing the credibility of qualitative research over the last few years. This idea is echoed by Jones (2004a) who suggests that attempting to apply quantitative terminology to qualitative reviews leaves qualitative researchers at risk of losing much of the ground that they have gained over the last decade.

A number of tools are available that propose various models for evaluating research studies using qualitative approaches. Such guidelines provide useful information in terms of reviewing many studies. However, research with people with dementia has its own unique methodological and ethical considerations and, for this reason, a set of criteria was developed specifically for use with this type of study. Production of these criteria was influenced by the work of Popay et al (1998), Department of Health (2001a), McCormack (2001a), McCormack (2002), Bartlett and Martin (2002), Webb (2003) and Jones (2004a). A rating scale of level one to level three has been used to assess how closely identified papers met the criteria. Papers categorised as level one met the criteria most closely whilst level three studies were least consistent. It is recognised that some studies will have been published in more detail elsewhere and that omissions may be due to constraints of word limits.

Popay et al’s (1998) assertion that flexibility rather than standardisation is the hallmark of good qualitative methodology influenced the approach taken to this review. The value in taking a pragmatic approach lies in its inclusionary nature which is vital particularly when considering a disadvantaged group whose voices are not often clearly heard. It is argued by Jones (2004a:97) that using qualitative methods for review embraces the “richness of human experience” and allows a full hearing of groups
that are frequently marginalised. In addition to considering review methods, qualitative researchers are also becoming much more aware of the value of meta-synthesis. Considerable debate exists in the literature about the extent to which qualitative research is amenable to meta-synthesis. Sandelowski et al (1997) argue that summarising qualitative findings has the potential to destroy the integrity of individual studies. Equally, there is a strong counter argument from authors including Sherwood (1999), Silverman (1997) and Britten et al (2002) that if qualitative researchers do not begin to develop their capacity in meta-synthesis there is a risk that they will continue to accumulate an ever growing number of studies which will remain in isolation and fail to influence either strategy or practice. In this era of evidence based health care, Thorne et al (2004) suggests that there is a real need to develop understanding and application of meta-synthesis to qualitative work. Whilst fully accepting this proposition, the review of these studies reveals that they focus on diverse aspects of dementia with the result that there is an insufficient body of work on any subject to indicate that meta-synthesis would be of real value.

Phase two provides a review of work in the area of researching with people with dementia. The following section addresses ways in which these studies have managed some of the central tenets that have been identified in the criteria as contributing to conducting ethical and meaningful research involving people with dementia. As stated, findings are summarised rather than synthesised as the volume of work in each area remains low.

**Aims and Participants**

Studies were assessed against criteria which required that the aims of the study should be clearly stated and justified. Participants should have been selected in a way that allowed the best chance of answering the research question. Recruitment processes should be sensitive to the needs of this group and adopt an inclusive philosophy.

**Aims**

In every case the researcher had documented a clear aim for the study. All aims were framed in terms that implied that the researcher was investigating from the perspective of the person with dementia. This demonstrated that in each case the research could only reasonably be conducted with people with dementia.
Methods of Recruitment

Recruiting people with dementia to a research study demands a level of sensitivity beyond that required in many cases. Key issues exist that need to be considered early in the process. It is essential to ensure that an inadvertent disclosure of the diagnosis of dementia is not made during recruitment. Researchers also need to consider the way that participants are selected to ensure an element of inclusivity. It is crucial to achieve a balance between using a recruitment process that respects the individual whilst not causing them undue anxiety or concern.

Recruitment processes generally involved purposive or convenience sampling, which is reasonable for studies of this nature. Only the study by Aggarwal et al (2003) claimed to use random selection, although the procedure is not described. Discussion of the sampling and recruitment process is notably absent in several cases (for example Sabat 2002a, Proctor 2001, Snyder 2003). A number of studies selected participants who used services specifically for people with dementia, for example Pearce et al (2002) selected people attending memory clinics; Phinney et al (2002) recruited participants from a geriatric research centre and an early diagnosis support group; Katsuno (2003) worked with people attending a dementia specific adult day and residential care centre. Although it can be argued that attendance at a dementia care facility does not ensure that the person with dementia is necessarily aware of their diagnosis it is suggested that this is a higher probability than would be the case when selecting people from other areas.

Other authors are less explicit about how potential participants were selected. Werezak and Stewart (2002) recruited from unspecified agencies and Proctor (2001) reports only that participants were attending a day hospital. Two studies investigated care of people with dementia in acute hospitals used totally different approaches. Tolson et al (1999) used a strategy of asking all older people who were consecutively admitted to medical or care of older people wards to complete a cognitive assessment. People who produced two low scores were invited to be involved in the next stage of the study. This method of selection is not justified in the paper and does raise questions about labelling of people with acute physical health problems as having dementia. It is not entirely clear whether this label was shared with participants. Norman (2003a) recruited patients in an acute hospital on the basis that they had been labelled as having memory problems either by nursing staff or in the medical or nursing notes. Norman provides a sound justification for her choice in stating that patients labelled by staff as having dementia, whether this is accurate or not, were constructed in terms of this label and would therefore
be treated in a similar way to those with a formal diagnosis. The latter approaches could be considered to increase the risk of inadvertent disclosure, whether confirmed or not, during the recruitment process.

When working with people with dementia there is a need to balance respect for the individual with using recruitment processes that are inclusive and do not cause undue anxiety and concern. Most studies used some type of “third party” during the first stage of recruitment, most commonly these were care staff or family members. A number of researchers asked care staff to identify people using their service who would be suitable to participate (for example Bamford and Bruce 2000, Mills 1997). This process could be viewed as assisting appropriate selection; equally it has the potential to introduce an element of bias through staff selection. Bamford and Bruce (2000) addressed this issue by allowing other interested users to join their discussions. A small number of researchers would only recruit participants who had a next of kin or spouse who was willing to take part (for example Phinney 2002a, Pearce et al 2002). Recruitment into the study of Graneheim and Jansson (2006) involved seeking consent from relatives. Participants were not informed of the study in advance, although they are reported as not objecting to being interviewed. Such approaches bring into question the respect for an individual’s personhood and belief in the value that they bring to the study.

A study by Svanstrom and Dahlberg (2004) investigating the lived experience of dementia for spouses where one is diagnosed with dementia, recruited people with dementia from a range of local services. These authors state that it was the healthy spouse who made the decision to take part (for example Phinney 2002a, Pearce et al 2002). Recruitment into the study of Graneheim and Jansson (2006) involved seeking consent from relatives. Participants were not informed of the study in advance, although they are reported as not objecting to being interviewed. Such approaches bring into question the extent to which the personhood of individuals was respected.

Use of a “third party”, who already knew participants, was used frequently. Initial information was provided by care staff in studies by Pratt and Wilkinson (2001), Werezak and Stewart (2002) and Mason et al (2005). This process could be seen as reducing coercion and so may be considered good practice. One drawback is noted by Pratt and Wilkinson (2001) who report that it led to an exceptionally slow period of recruitment. It is notable that following first contact from a “third party” many researchers chose to communicate directly with people with dementia, for example Mason et al (2005) attended a support group to explain their study in more detail. Other studies, for example Burgener and Dickerson-Putman (1999) recruited via family care givers. It may be suggested that this approach borders on paternalistic and compromises the
personhood of individuals. In addition, it makes the unfounded assumption that people with dementia and their carers have good relationships (Pratt 2002).

**Inclusivity**

Inclusion of people with dementia is becoming well established as a necessity. It is noted by Keady (1996) and Downs (1997) that researchers have tended to concentrate their work on those in the earlier stages and this approach remains evident. A number of studies reported the level of cognitive impairment of the participants with most using the Mini Mental State examination (MMSE) (Folstein et al 1975). Most participants had recorded MMSE scores of eighteen or above indicating mild to moderate dementia. Exceptions were Sabat (2002a) who engaged with a person with an MMSE of nine and Marzanski (2000) who included people with MMSEs ranging from seven– twenty nine. Some researchers made a conscious decision not to investigate the level of cognitive impairment of participants. This may have been on the grounds that MMSE score does not necessarily correlate with an ability to communicate one’s views. The fact that most of this type of research concentrates on people with less severe dementia is highlighted by several authors including Hubbard et al (2003), Phinney et al (2002) and Bamford and Bruce (2000) who suggest that methods for inclusion of those with more advanced impairment need to be developed further.

It is evident that most researchers in these studies have given considerable thought to the selection and recruitment of participants. Some have used strategies such as the “third party” to minimise risk of anxiety or feelings of coercion. Equally, a small number of studies have employed processes that are questionable particularly in terms of selecting people who are likely to be able to answer the research question and in terms of ensuring participant choice. Virtually all participants had a relatively high level of cognitive function and several authors point to the need to include people with more advanced dementia. These studies indicate that there is a value in involving people with a pre-existing relationship with potential participants in the recruitment process. However it is argued that this approach must be carefully balanced in order to prevent inadvertent exclusion or paternalism. It is recognised that there is a need to expand the scope of research to include people with more advanced dementia.
Chapter One

Research Design

Criteria related to research design concerned the extent to which the method selected was appropriate to the research question. A high level of flexibility, particularly in terms of data collection, was required in order to accommodate the potentially varying needs of participants. The process of moving from data to interpretation should be explicit.

Research Method

Methods used in the studies varied considerably, forty used purely qualitative methods whilst five employed mixed qualitative and quantitative techniques. Use of predominantly qualitative methods may be a reflection of the professional backgrounds of the researchers many of whom worked in the arenas of nursing or social care and research. It is suggested that this group are likely to be conversant with qualitative methods and therefore be better equipped to engage in person focused enquiry. Only one researcher was noted to be from a medical background, Marzanski (2000) who worked as a Specialist Registrar in Old Age Psychiatry. He bravely stepped from the biomedical model into the qualitative paradigm. However, the study perhaps indicates some discomfort with this approach in its apparently fairly rigid application.

Explanation of the detail of research design is mixed. Bamford and Bruce (2000) explain each step of their research in detail, an approach followed by Pratt and Wilkinson (2001) and Gillies (2000). Other authors provide a much less comprehensive explanation, for example the work of Sabat (2002a) and Snyder (2003) give only a perfunctory overview of the research process.

Data Collection

Data were most commonly collected through interviews. Several studies used other methods of data collection to supplement interviews. For example periods of observation were completed by Phinney (1998, 2002a), Phinney et al (2002), Norman (2003a) and Nygard and Starkhammar (2007); Bamford and Bruce (2000) and Mason et al (2005) engaged in group discussions; video recording was used by Mason et al (2005), Vernooij-Dassen et al (2006) and Daniels et al (2007) whilst Tolson et al (1999) chose to review clinical documentation. Positive and negative attributes of these data collection techniques are not debated in detail in any of the papers. It is suggested by Clarke and Keady (2002) that
there are key criteria that need to be met to ensure effective data collection with people with dementia. They consider that it is vital that the approach of the researcher is positive and creative and that the process enables enough engagement between researcher and participant to allow confirmation of issues.

Effective methods for conducting interviews with people with dementia have been the subject of much debate in the literature. There are a number of issues that need to be taken into consideration when conducting any qualitative interview. There are others that are particularly pertinent to interviews with people with dementia. These include whether the person should be interviewed alone or whether to have another person present to offer support, ways in which questions are asked and the number of interviews required.

It is suggested by Pratt (2002) that carers can be valuable collaborators in dementia research whilst equally cautioning against assuming that the person with dementia will want to be accompanied. Pratt suggests a compromise position of combining interviews with and without carers. This idea is supported by Preston et al (2007) who interviewed twelve people of who five chose to be accompanied by their spouse. In these interviews the spouses were encouraged to make their contributions after the interview, presumably to ensure that they did not detract from the primacy of the person with dementia. Most interviews were conducted with participants unaccompanied but it is not always clear if they were given the choice to include a supporter. Phinney (2002a), Pearce et al (2002) and Clare et al (2005) chose to interview people with dementia and their partners separately. These authors made it a prerequisite that partners had to be willing to be involved and imply that partners’ interviews were used to corroborate the information supplied by the person with dementia. Whilst having a different perspective may have added depth to the data it may be considered that Phinney’s (2002a) request that partners report what they thought the person with dementia was experiencing does appear rather speculative. In the case study of Hellstrom et al (2005) a couple were interviewed separately but asked about the same themes. Following this the couple joined in the process of co-construction which provided an agreed account that reflected their experiences. This approach could be viewed as epitomising respect for each individual in enabling each to give their own view and then collaboratively agreeing on the final version.

An alternative approach was taken by Daniels et al (2007) who conducted a single case study into the marital relationship of a couple, one of whom had Alzheimer’s disease. Each of the three interviews were joint and the focus was very much on the marriage with the couple being left to
begin to talk about the Alzheimer’s disease when they felt it was appropriate. Again, this approach showed a high level of respect for both the individuals and their relationship. It is noted that there are potential pitfalls when including others, in this case the main visitor, in the interview process. These are identified by Tolson et al (1999) who report that the presence of the visitor, generally a family member, detracted from the ability of the person with dementia to communicate fully.

Interviewing people with dementia is clearly a venture that requires skill and sensitivity. It is noted that some still question the value in seeking the views of this group. This is highlighted by authors including Goldsmith (2002) and Clarke and Keady (2002). These authors are adamant that people with dementia, even in the more advanced stages, have a desire to communicate and that it is the responsibility of the researcher to find ways in which this can be enabled.

A range of interview styles have been suggested. Keady and Gilliard (2002) advise that largely unstructured interviews can be used to build a trusting relationship between participant and researcher which may enable the participant to reveal sensitive information. A semi-structured approach using a set of predetermined questions is discussed by Harris and Durkin (2002). They suggest that this can be valuable in ensuring some parity when interviews are being conducted by different researchers. An example they give is of interviews by two researchers, one of whom was a clinician and one of whom had Alzheimer’s disease. A direct questioning stance is advocated by Young (2002) who states that when involving people with early dementia this approach can show a genuine desire to find out their views and thus enhance their self esteem.

Studies reviewed employed a variety of interview techniques. Style of interview varied from the very structured approach used by Burgener and Dickerson-Putman (1999) and Marzanski (2000) both of whom delivered a consistent set of questions, through the semi-structured approaches of Pearce et al (2002), Mason et al (2005) and Werezak and Stewart (2002), to the unstructured format of Sabat (2002a) and the counselling base adopted by Mills (1997). Extracts of data suggest that perhaps the skill of the interviewer is more critical to success than the interview approach used. For example Pratt and Wilkinson (2001) used interviews with a clear topic guide. They had planned to interview people twice but due to various constraints this was not always possible. However, the data they present demonstrates how, with the right approach, people with dementia can be assisted to provide rich insights into their experiences. Participants in a study of involvement in activity by Phinney (2006) enabled participants to express their views by supporting them to give narrative accounts of their
own experiences. The counselling approach to interviews is advocated by Mills (1997) who used it to good effect in illuminating the narratives of eight people described as having moderate to severe dementia. Nelson-Jones (1993) discusses the concept of using counselling skills in qualitative research suggesting that transferable skills include altruism, humanism, intellectual curiosity and people orientation. Although these facets are not discussed, they are clearly represented in the work of Sabat (2002a) in his interaction with a person with relatively advanced dementia. To enhance engagement and stimulate discussion, Aggarwal et al (2003) and Norman (2003a) both used “prompts” such as photographs to trigger conversations with participants.

Most interviews are reported to have been tape-recorded with permission of the participants. This appears to have been relatively unproblematic with no researchers documenting particular concerns. This may be due to the fact that most participants had a relatively high level of cognitive functioning and so retained a sound memory of this type of equipment. In contrast, video recordings appeared to require a greater level of explanation and it is possible that older people involved in the studies were less familiar with this slightly more modern technology. Video recordings were used by Mason et al (2005) in a study of support groups and Daniels et al (2007) when interviewing a couple. Use of this technique is investigated in detail by Cook (2003) who used video recordings with older people with dementia in a residential care setting. Cook (2003) graphically describes her work in ensuring that the participants were familiarised with the equipment and her sensitivity in recording. Mason et al (2005) video recorded entire support groups but the way in which this was introduced and the impact that it had on group dynamics is not discussed in detail.

A number of studies involved a series of interviews, although this does not appear to be an absolute pre-requisite to achieving engagement with resulting rich data. This is evidenced by the work of Gillies (2000) who interviewed most participants only once but clearly enabled participants to express their views in considerable depth. Other researchers used multiple interviews, such as Phinney et al (2002) who conducted three interviews with each participant to the extreme of Mills (1997) who undertook between thirteen and twenty five interviews. It does not appear that more interviews necessarily leads to increased quality of data.

Data collection largely involved interviews with participants. Styles ranged from highly structured to conversational approaches and the number of interviews conducted varied from one to twenty five. Involvement of significant others in the interview process has been
discussed and advantages and disadvantages noted. Literature offers some fairly prescriptive guidance on the way in which interviews with people with dementia should be conducted. However the guidance is, in places, contradictory. An idea that emerges from these studies is that, whilst guidance is available, the key element that enables effective data collection, regardless of espoused style, is the personal manner and approach of the individual interviewer.

Data Analysis

Whilst there is a wealth of guidance about how to include people with dementia in research, there is a marked absence of work that focuses on data analysis. None of the papers reviewed cite the analysis process as a particular challenge. Quality of explanation of the approach to analysis ranges from virtually absent (for example Marzanski 2000, Sabat 2002a) to comprehensive (for example Pratt and Wilkinson 2001, Phinney 2002a). It is noted that the lack of detailed description of the analysis process does not necessarily detract from the findings presented, although, it clearly leaves a question as to how the findings have been developed.

Both qualitative and quantitative methods of data analysis have been employed. Quantitative work generally uses fairly simple statistical approaches and, on the whole, straightforward techniques have been used to analyse data that supports qualitative findings (for example Katsuno 2003). Qualitative data has mainly followed well established methods. It is noteworthy that Mason et al (2005) are unique amongst these studies in paying detailed attention to the non-verbal communication of participants. This is perhaps surprising given the assumed difficulty that people with dementia have in expressing themselves verbally.

Interpretation of data does not appear to have caused major concern. Several authors returned to participants to check their understanding, for example Werezak and Stewart (2002) used second interviews to “validate” categories and Mills (1997) took emerging themes back to participants to deepen understanding. Steeman et al (2007) initially used grounded theory to analyse their data. They concluded that this was not wholly satisfactory and subsequently added elements of narrative analysis. This had the effect of strengthening their analysis considerably, providing a new level of understanding. It is perhaps surprising that, almost entirely, mainstream qualitative approaches to analysis have been used. It may be considered that other methods to aid the expression of the thoughts of participants would have been explored, such as the use of poetry, as demonstrated in the work of Killick (2001, 2002).