

Stories of professional care: Narrative analysis of accounts from people with dementia

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ABSTRACT

UK dementia care policy and practice guidelines (e.g. Department of Health, 2012; National Institute for Health and Care Excellence, 2011) construct narratives of disease epidemic, financial and emotional burden and poorly theorised and operationalised aims. From a social constructionist perspective these public narratives create the space in which individual care experiences of people with labels of dementia take place. A review of current representations of user experiences in dementia care research points to a significant gap, particularly within academic research, where these experiences remain seldom heard, under-theorised and de-politicised.

The current research aimed to elicit narrative accounts of the professional care experiences of people with labels of dementia to contribute to the development of dementia care theory and practice based upon, and responsive to, individual experiences. Accounts were elicited across voluntary and statutory dementia services via three one to one unstructured interviews, and a group of five service users meeting over three occasions. Narrative analysis of participants' accounts attended to personal and collective stories told and the dialogical relationships between narrator and audience within the broader socio-political context (Phoenix, 2008; Stephens & Breheny, 2013).

The communicative and narrative abilities of older people with labels of dementia were demonstrated as participants' (co)constructed preferred identities, took up, were assigned and attempted to resist a range of positions (e.g. experienced, independent, passive and vulnerable) and imagined alternative possibilities for care, such as interdependence. Reder and Fredman's (1996) 'relationship to help' framework was drawn upon to make sense of interactions in participants' accounts between diverse perspectives and life histories with a much smaller repertoire of public narratives associated with dementia care. In privileging experiential knowledge, and attending to the language used by people with labels of dementia, the findings indicate possibilities for citizenship models of dementia based upon relational support, personal agency and compassion.

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1. INTRODUCTION

The care of people with labels of dementia (PWLD) is a growing concern for ageing societies. The Prime Minister's 'Dementia Challenge' (Department of Health (DoH), 2012) calls for action in research and quality of care. In the current UK context, approximately 800,000 people have been diagnosed with dementia (Alzheimer's Society (AS), 2013), and the evidence points to inadequate care provision:

Despite the number of people living with dementia, and the associated costs, numerous reports from the National Audit Office (NAO, 2007; 2010), Public Accounts Committee, regulators, NHS Atlas of Variation (NHS Right Care, 2011) and Alzheimer's Society show that many people with dementia are being let down. Despite the significant spend on dementia, this is not being developed effectively and too many people are not provided with good quality care and support that meets their needs and aspirations. (AS, 2012a:4).

Across Western societies poor dementia care has been attributed to a range of factors. These include the persistence of negative perceptions of dementia held by professionals (Kontos & Naglie, 2007), a lack of investment in education for practitioners (Cohen-Mansfield & Mintzer, 2005; Sung, Chang & Tsai, 2005) and current pressures on health and social care resources (Lister, 2013). The latter is more generally a key contributor to quality of care (e.g., Hall & Kiesners, 2005; Mark, 2002).

But what constitutes 'good quality care'? Quality is often defined in terms of broad principles such as privacy, dignity, independence and person-centeredness, which can become mere buzz-words if not operationalised or a shared meaning developed (Help the Aged, 2007). As Fox, Lafortune, Boustani and Brayne (2013) outline, dementia is a broad term for a syndrome under which a collection of clinical features are subsumed, for which there is currently no prevention or cure. In the absence of a cure, maintaining or improving quality of life is arguably the central, overarching principle of care. However, evidence suggests a disparity

between service provider and user views about what this might constitute (Congdon & Magilvy, 2002).

Through this introduction to the literature I outline the current UK context for dementia care, at both a practice and conceptual level, and consider how this relates to user experience. I argue that, from a social constructionist perspective, a gap in the evidence base representing the views and experiences of PWLD limits the possibilities for improving the quality of care experiences. Particular consideration is given to what we know about how PWLD make sense of their experiences of care, and what we might need to know about their understandings of care experiences if we are to develop useful and meaningful services. To this end, a formal literature review strategy in relation to user experiences of dementia care is presented in section 1.3 below.

1.1. Contextualising the Research

1.1.1. Personal context

Each research endeavour “can be understood as a tacit and intentional positioning” (van Langenhove & Harré, 1999:31). This is particularly relevant to this research endeavour, which seeks to position PWLD as key stakeholders in the research. Through all actions and speech acts we may both position ourselves and/or be positioned by others, for example, by drawing upon available discourses to make our words meaningful to ourselves and others (Davies & Harré, 1990).

To contextualise my personal position in this area of practice and research, the care experiences of PWLD have been integral to my development as a Clinical Psychologist (CP). As a young person I undertook part-time care work in private sector residential homes for older people, many of whom were diagnosed with dementia. This experience raised questions regarding why people were placed in this type of setting, in which they were often left to languish and spoken to chiefly to police the physical routines of care. Both at the time and since then, I have found myself asking who is this care *for*? And what is its purpose? To keep

people alive? To keep people safe and clean? For anything more than this – for the families of residents, or for the residents themselves? These questions remained with me as I worked as a Trainee CP in a Cognitive Impairment and Dementia service, where dementia diagnoses were offered in the relative absence of ‘treatment’, and as we witness care scandals that call basic functions of care, such as providing safety, into question (e.g., NAO, 2007).

Through this thesis I am seeking to use the knowledge and skills from my professional training to understand something of the dementia care experience, inspired by the questions I first asked over a decade ago – which, as demonstrated by the literature review below, remain to a large extent unanswered.

1.1.2. The broader context: Socio-cultural and historical

Public awareness, or arguably collective fear, of ageing with dementia is a feature of ageing societies in the Western world (de Boer, Hertogh, Dröes, Riphagen, Jonker & Eefsting, 2007).

Such fears are demonstrated and constructed within UK dementia policy, which aims in part to increase public awareness of dementia. For example, the Prime Minister’s ‘Dementia Challenge’, (DoH, 2012:3) asks us to:

Imagine feeling confused and afraid because close friends and relatives seem like strangers; being unable to leave the house alone because you might not be able to find your way back; or seeing the fear in your loved one’s face, as they struggle to make sense of familiar surroundings.

The rhetoric evokes a disease epidemic, with the associated burdens:

Among the over-55s, dementia is feared more than any other illness. And at an estimated £19 billion a year, the cost to our economy is huge. It is estimated that this is higher than the costs of cancer, heart disease or

stroke. We have not only a moral imperative to improve dementia care – there is a strong financial one too (DoH, 2012:4)

Current UK policy narratives echo those of some thirty years ago, for example within the 'Rising Tide' governmental report (NHS Health Advisory Service, 1982), which evoked images of dementia as a disease of epidemic proportions. The history of 'senile dementia' as a state of madness associated with old age can be traced back to Ancient Greece, and categorisation of a clinical syndrome associated with forgetfulness of newly acquired memories in later life to the early nineteenth century (Henderson, 1986). However, it is only since the 1980s that medical research has come to dominate formal models of dementia (Bond, 1992), despite a lack of reliable and valid empirical evidence to date (Fox et al, 2013; Harding & Palfrey, 1997).

The emergence of the rhetoric of a dementia disease burden in recent decades can be contextualised within ongoing tensions between predictable - yet apparently surprising to successive governments - population growth in older people (Hilton, 2010), historical therapeutic nihilism in relation to the over-50s (e.g. Freud, 1905), and the enduring view that resources are wasted on the elderly. Despite recently introduced legal protections against age discrimination (The Equality Act 2010), narratives of the un-deserving old, perceived to take from society without contributing, remain influential, whilst the costs of meeting social and health care needs for an ageing population inevitably rise (Hilton, 2010). One response to this apparent dilemma is to side-step the cost and complexity of co-ordinating effective health and social care, via a highly visible race for a biomedical dementia cure. However, based on current evidence (see Fox et al. 2013 for a recent overview), this race constitutes little more than a hope that such a financially and politically expedient solution is within reach. In the meantime, the medicalisation of dementia has legitimised, particularly at the time of the rise of the medical model in the 1980s, the use of physical and chemical restraint to 'treat' the 'demented' who might otherwise pose a threat to social order (Lyman, 1989)

UK policy narratives thus position PWLD as a financial burden and as sufferers - vividly conjuring a person both frightened and frightening - in a societal context of exclusion and stigma associated with older people with memory problems (Sterin, 2002). However, de Boer et al.'s (2007) review of the international literature of the patient's perspective on dementia "gives no solid support to the widespread assumption that dementia is necessarily a state of dreadful suffering" (de Boer et al., 2007:1021). Instead, the authors argue that the fears the public may hold about dementia – such as loss of autonomy, and the burdening of family and state – are fears of inadequate care.

1.2. Definitions

'PWLD', and 'professional care' are terms used to identify who and what the chief concerns of the current research are.

1.2.1. People with Labels of Dementia

The current status of biomedical dementia research points not to a disease but a syndrome, the clinical features of which are continuous, a result of multiple factors, and diagnosed via criteria which rely upon societal norms for cognition and function (Fox et al., 2013). Whilst allowing for individual differences in the progress of dementia, standard biomedical definitions of dementia are essentialist, do not tend to incorporate the impact of broader factors such as the social context of the person, and encourage a focus on dementia cure or prevention, whilst in the meantime the care of people who need it is neglected (Fox et al., 2013; Sabat & Gladstone, 2010).

This biomedical definition of dementia is typical:

The term 'dementia' describes a set of symptoms which include loss of memory, mood changes, and problems with communication and reasoning. These symptoms occur when the brain is damaged by certain diseases, including Alzheimer's disease and damage caused by a series of small strokes. Dementia is progressive, which means the symptoms will

gradually get worse. How fast dementia progresses will depend on the individual person and what type of dementia they have. (AS, 2012b:1).

Within the medical model, dementia is diagnosed by sub-type according to the assumed underlying brain disease, typically via internationally standardised diagnostic criteria recommended by the National Institute for Health and Care Excellence (NICE, e.g. 2006; 2011). Dementia subtypes include Alzheimer's disease (AD), Vascular dementia, Dementia with Lewy bodies, Frontotemporal dementia, and other rarer diseases that may lead to dementia, including Korsakoff's syndrome, HIV/AIDS, and Creutzfeldt-Jakob disease. Some people with Multiple Sclerosis, Motor Neurone disease, Parkinson's disease and Huntington's disease may also develop dementia. Mild Cognitive Impairment (MCI) is defined as cognitive decline greater than expected for an individual's age and education level, which does not significantly interfere with activities of daily living but, whilst not a diagnosis of dementia, can later develop into dementia (NICE, 2006). People diagnosed with MCI are included in the current research as in my clinical experience, and congruent with practice guidelines (e.g. NICE, 2006; 2011), care services for PWLD are accessed by people labelled with MCI.

Differential dementia diagnoses are associated with core neuropsychological and behavioural features. For example, a primary progressive amnesia is associated with AD (McKhann, Drachman, Folstein, Katzman, Price & Stadlan, 1984), whereas executive and visuospatial dysfunction is associated with Dementia with Lewy bodies (Knopman, Boeve & Petersen, 2003). However, the diagnostic process has been critiqued on several grounds, including reliability and validity (Fox et al, 2013; Harding & Palfrey, 1997), the decontextualisation of the person's cognitive and communicative functioning, and over-reliance on neuropsychological test batteries (McLean, 2007; Sabat, 1998; 2001; Sabat & Gladstone, 2010). Harding and Palfrey (1997) postulate that the medicalisation of dementia serves to meet the needs of society by seemingly offering the possibility of a 'cure', not just for dementia but for its associate, old age, and perhaps ultimately for death itself.

An operational definition of what constitutes 'PWLD' within the scope of the current research is 'people in receipt of dementia care services'; this is congruent with evidence-based guidance that "should not be regarded as applying solely to people with a formal diagnosis of dementia. The support it advocates should be available for all people with cognitive impairment that could be linked to probable dementia" (NICE, 2013:1).

The conceptual framework I have adopted for dementia incorporates neurological processes associated with cognitive and functional abilities, within a socially constructed experience. Discrete dementia disease-labels are critiqued in regards to both the evidence and conceptual basis, which at present is more consistent with a continuous range of brain pathologies, (e.g. atrophy, vascular lesions, and build-up of proteins) and functional abilities. These constitute a range of 'syndromes', associated primarily with ageing, alongside currently poorly understood individual factors (Fox et al., 2013; Rothman & Greenland, 1998). In the current research, the effects of neurological impairment upon the experiences of PWLD are not disregarded, but understood in interaction with a complexity of factors – both proximal, such as physical health, family context and social psychology and distal, for example public narratives and the structures of health and social care.

Emergent critical research examining embodiment in dementia attends to a breadth of issues related to the experience of being situated within one's body over a life-time. This includes the culturally situated body and valuing of cognitive and functional ability, youth and the cult of the body, the social construction of surveillance and management of the body in dementia care, and also the potential for creativity and bodily self-expression (Martin, Kontos & Ward, 2013). The capacity of the body to engage with the world, for example through artistic practices, aversion to particular foods, recognition of familial bonds and use of gesture in interaction, exemplify 'embodied self-hood' and agency, regardless of cognitive deficits associated with underlying pathology (Kontos, 2013).

From a social constructionist perspective I am concerned with questions of the extent to which formal representations of dementia, such as diagnostics and

health care policy, construct the experience of being cared for in a dementia context, and the identity of the individual being cared for. Within such an inquiry, “neurology is not the only (or even necessarily the most important) factor in dementia”. (Baldwin, 2008: 226). Kitwood (1990) argues that biomedical research fails to account for around seventy percent of the variance between neuropathology and the presentation of dementia. Consequently, person-centred models of dementia care consider the experience of dementia as multidimensional, including how neurological impairment, biography/life history and social psychology are uniquely constellated in a person's life (Kitwood, 1997). Kitwood aimed to shift the focus of dementia care from disease and its treatment towards the enablement of ‘personhood’, referring to the status relationally bestowed upon a person by others, including recognition of the uniqueness of each, respect and trust, and the effects upon identity, personal agency etc.

Whilst person-centred models aim to broaden the conceptual basis of, and care practices related to, dementia, there is a poor record of operational definitions and evidence for implementation in the literature (Epp, 2003). Person-centred models also tend to neglect the socio-political context of the socially constructed experience of the PWLD (Adams, 1998). Adams argues for theoretical and practical advances in person-centred care via attention to the language used by PWLD, alongside their carers, to understand the ways that dementia and care are constructed.

1.2.2. Professional Care

This research is concerned with the professional care experiences of PWLD. Current UK policy guides dementia care via strategic frameworks such as the National Dementia Strategy (DoH, 2009a). The implementation is spread across health, social and voluntary care services, supported by national guidance and standards (e.g., NICE 2006; 2011; 2013), although often poorly integrated in practice (Goodwin, Sonola & Thiel, 2013). The recent British Psychological Society ‘Dementia Pathways’ document (BPS, 2013) collates current good practice to inform a pathway for dementia care. The pathway promotes a broadly

psychological framework for service development and care provision, identifying a range of care services across settings – for example, non-pharmacological interventions for problematic behaviour change associated with dementia, and caring for PWLD on hospital wards and at home.

However, defining ‘dementia care’ is not straightforward; there are social and practical implications to the use of language (Burr, 2003). For example, the disease-based narrative of dementia as degenerative and terminal can deny people basic care, such as antibiotics (D’Agata & Mitchell, 2008); i.e. the choice of language affects the power available to the person with dementia (Behuniak, 2010; Sabat, 2003). Baldwin (2008) theorises policy as the realisation of collective narratives, arguing that they “create the space within which individuals exercise their citizenship rights. In so doing, they also create formal representations of their identity.” (p. 224). From a social constructionist perspective, this raises questions regarding the extent to which policy constructs the experience of being cared for in a dementia context, and the identity of the individual being cared for.

Definitions of dementia care can be thought of as relating to two key aspects; the purpose of the care and the form in which the care is delivered. The wide range of dementia care services operating in the UK, from voluntary sector ‘dementia advisors’ to local authority personal support packages, raise the question of what dementia care is ostensibly *for*. For example, does care aim to meet social and emotional support needs, (e.g., Snyder, Jenkins and Joosten, 2007), or enable independence and safety (e.g., DoH, 2009a)? Or does the medicalisation and identified ‘care needs’, such as residential care, equate to a form of social control over those “who would otherwise challenge the orderly nature of society” (Harding & Palfrey, 1997:143)?

Harding and Palfrey (1997) draw upon Armstrong’s (1983) *The Political Anatomy of the Body* to argue that those defined as ‘demented’ are positioned beyond the self-control engendered in modern societies, appearing to contravene its most basic rules and challenge the entire fabric of society. In their view, the rhetoric of a dementia epidemic and societal burden used in dementia policy (e.g., DoH,

2012) invokes a perception that society's overall health will suffer, and allows PWLD to be positioned as without self-control and, thus, needing to be controlled. The authors argue that both institutional dementia care, and less costly community health and social care, are methods of such control. This perspective again raises questions about who dementia care is for, and points to the potential value of asking PWLD themselves, as opposed to designing services *for* them or for those around them.

In regards to its form, Helgesen, Larsson and Athlin (2010) outline the breadth of factors comprising professional care, including personnel, leadership culture, and the physical care environment. Care can refer to assistance with the most basic of physical tasks such as eating, toileting, bathing, and walking (Armstrong & Armstrong, 2003). Twig (1997) argues that from a professional perspective care is defined in terms of tasks which can be operationalised in written standards; for example, in regards to how much time can be spent on a given task and the prescribed procedures. Zagier Roberts (1994) draws upon systems and psychoanalytic perspectives to consider how we define the *primary task* of human services. Defining the primary task(s) for institutions determines resource allocation and prioritisation of activities (Zagier Roberts, 1994). An examination of 'dementia care' and its guiding policy soon illuminates the difficulties in defining the primary task(s) of dementia care. For example NICE (2013) quality standards identify a range of possible care tasks within a dementia care pathway, including individual support via personalised care plans to address physical and mental wellbeing and independence, carer support, community participation and pharmacological and non-pharmacological interventions for 'behaviour that challenges' and for cognitive functioning.

Psychoanalytic perspectives (e.g. Menzies-Lyth, 1959), point to processes that may influence the ways in which we define care tasks. For example, the recommended routine of biannual, medicalised reviews for people diagnosed with dementia (NICE, 2011), might serve as defence against existential anxieties around ageing and deteriorating brain function by offering a seemingly organised and controlled management of such processes.

'Caregiving' is also a relational process. The sociologists Pearlin, Mullan, Semple and Skaff (1990:583) define caregiving in these terms:

Whereas caring is the affective component of one's commitment to the welfare of another, caregiving is the behavioural expression of this commitment.

Furthermore, from a systemic perspective, Reder and Fredman (1996) consider the 'relationship to help', theorising the role of previous experiences of care giving and receiving, which give meaning to subsequent episodes of care, and the interactions with the beliefs and experiences of others in the caring relationship. Much dementia care research focuses on informal care-giving relationships which surround PWLD, often focusing on the 'care for the carer' to the neglect of the views of the person with dementia (Cottrell & Schulz, 1993). For many PWLD their caregivers are non-professionals, such as family and friends (DoH, 2009a). There is inevitable overlap with professional care, as family caregivers often negotiate with and are required to become familiar with, or indeed expert in, medical care providers and procedures (Ayres, 2000).

1.2.3. Mental Capacity

Conceptualising and researching the professional care experiences of PWLD is tightly bound with the construction and practices related to 'mental capacity'. Mental capacity is broadly defined as the ability to make decisions for oneself, and in England and Wales the Mental Capacity Act (MCA, 2005) provides a statutory framework to protect those over sixteen years old who may not be able to do so. A person's capacity may be affected by factors such as a learning disability and/or illness and injury affecting cognitive functioning, alongside the context and nature of the decision to be made (MCA, 2005). The MCA outlines that assessment of capacity should be time and decision specific, and that the assessor both enables and considers the person's ability to understand, retain, weigh up and communicate the relevant information and decision made.

As outlined, dementia diagnoses are associated with decline in cognitive functions such as attention, consciousness and communication. Despite a rise since the 1990s of person-centred models of dementia care, it has historically been assumed that these factors strip the individual of their personhood and mental capacity (Cohen & Eisdorfer, 1986) and preclude involvement in research and care related decision-making (Helgesen et al., 2010; Hernandez, Robson & Sampson, 2010). The currently influential 'biomedical legal model' links dementia diagnoses and related cognitive impairment to a legal loss of personhood, restricting the definition of capacity, and arguably what it means to be human, to the capacity to think with self-awareness and rationality (Behuniak, 2010). A broader construction of capacity, encompassing compassion, i.e. balancing rights with protection (Behuniak, 2010), alongside conceptualising decision making as a relational process, offers an alternative, and informs the methods developed in the current research.

Having outlined the current context and theory informing dementia care in the UK, this Introduction subsequently focuses on literature pertaining to user experiences of professional dementia care.

1.3. User Experiences in Dementia Care Research

Methods to elicit older people's experiences as service users, particularly those with high social and health support needs, remain limited (Katz, Holland, Peace & Taylor, 2011), despite governmental guidance with explicit requirements for user participation (e.g. the National Service Framework for Older People, DoH, 2001). A review of UK policies and practice for the care of older people by the Institute for Public Policy Research (McCormick, Cherti, Clifton, McDowell, & Sachrajda, 2009) identified that user feedback surveys are in the main unsuitable for those with visual or communication impairments, alongside structural flaws in health and social care regulatory systems which tend to focus on minimum standards rather than user experience. McCormick and colleagues situated these limited opportunities for user feedback within a context of UK cohort beliefs in the over seventy-fives related to gratitude for universally free health and social care, low expectations and fear of service cuts if provision is criticised. The authors

concluded that uneven power relations between providers and users mean missed opportunities for service improvement.

1.3.1. Literature Review Strategy

The purpose of a formal review of the literature relating to user views of dementia care was to broadly establish what is known about the experience of dementia care from the perspective of PWLD.

The databases PsychInfo, CINHALL PLUS, Academic Search Complete, Science Direct, PubMed, and Web of Science were searched during August–December 2013 with no restriction applied to the date of article publication. Search terms were initially derived from the academic and health and social policy dementia literature outlined above.

The key search terms, were “dementia” combined with “professional care OR services” and “client attitudes”. Synonyms to key terms were also elicited within each database via index thesauruses. A summary of the complete search terms with all synonyms, and the inclusion and exclusion criteria for studies reviewed can be found in Appendix 1. Additional articles were found through cross-references and conversations with colleagues.

1.3.2. Summary of the literature

1.3.2.1. Current dementia care research

One hundred and forty titles and abstracts were returned and examined from the search strategy, of which 108 reported proxy representations of the care experiences of PWLD, and 15 pertained only to the dementia screening or diagnostic process rather than subsequent care. Proxy views were elicited, for example, via measuring carer views (Karlavish, Casarett, Probert, James & Clark, 2002) and relying upon staff ratings or observations of the behaviour, ‘symptoms’ or treatment of PWLD to evaluate care (e.g., Cohen-Mansfield & Werner, 1999; Lee, Jhoo, Lee, Kim, Lee & Woo, 2000; Mathews, Clair &

Kosloski, 2001; Rovner, Steele, Shmuely & Folstein, 1996). These studies often implicitly positioned PWLD as unable to share their experiences directly, but failed to account for why they chose indirect methods to evaluate user experience.

In dementia care literature and practice there are established methods for indirectly evaluating user experience where verbal communication is no longer available to participants. Kitwood and Bredin's (1994) Dementia Care Mapping method is an attempt to gain insight into the care experiences of PWLD by using observer evaluation of the relative wellbeing of the person with dementia, in particular attending to the quality of interpersonal interactions in the care relationship. Researchers such as Barnett (2000) have used this method to gain insight into the experiences of PWLD, and explicitly addressed its constraints alongside its value in including the experiences of all, regardless of verbal skills. Such a method can be a useful adjunct to direct means of eliciting user views, such as interviews. What is striking within the 77% of studies which report proxy methods of seeking user views is the absence of theoretical or even pragmatic justification for using indirect methodologies. Such indirect methodologies can reduce PWLD "to the status of object rather than legitimate contributor" (Cotrell & Schulz, 1993:205) and, whilst the literature comprises both UK and international samples, the methodologies frequently contravened the inclusionary aims of the MCA (2005).

The exclusion of PWLD from research is exemplified in a study in which only 'non-demented' residents were asked about their satisfaction with sharing residences with 'demented' residents (Teresi, Holmes & Monaco, 1993), and research in which only care givers were asked about their use of and satisfaction with medical and social services related to their family member with AD (Dello Buono, Busato, Mazzetto, Paccagnella, Aleotti, Zanetti & De Leo, 1999).

Wilkinson (2002) outlines the limited understanding and experiences of research methods that can enable the views of PWLD to be safely and usefully encouraged and made sense of. Whilst there is indeed a complexity to capacity and communication issues in dementia research, which necessitate appropriate

methodologies to maintain an ethical approach (Dewing, 2007), most studies did not appear to assess capacity for inclusion or attempt to enable people to communicate their experiences.

There was also evidence of reliance upon standardised outcome measures. Cohen, Hyland and Devlin (1999) evaluated the effects of a buddy programme between people with and without labels of dementia in a residential home. The study found that for PWLD depressive symptoms increased and satisfaction with the nursing home decreased over a six-month period, with no significant changes for the buddies without dementia. The study concluded that a helping network model between people with and without dementia labels cannot easily be adopted in residential nursing care. Through relying upon professionally developed outcome measures, the authors were unable to elucidate why dissatisfaction with the environment may have increased for PWLD, and what alternatives were indicated. By denying the value of experiential knowledge, mainstream research approaches, which privilege professional definitions of evidence and a positivist epistemology, risk separating behaviour from meaning. Beresford and Evans (1999) contrast such an approach to progressive alternatives which address the power difference between researcher and researched, and widen the definition of 'evidence' to include the interpretation of experience by both.

1.3.2.2. Current user experience in dementia care research

Only seventeen studies (twelve percent of those returned) directly included the experiences of PWLD. These studies considered a range of Northern European and North American dementia care contexts, such as residential, day care and support groups, using qualitative and quantitative methods to understand something of the experience of service users with dementia.

1.3.2.2.1 Context: Care settings and participants

Most of the seventeen studies comprise specific service or intervention evaluations based on the views and experiences of PWLD, in some cases solely, and in others triangulated with other stakeholders, such as staff. Snyder et al.

(2007) evaluated the effectiveness of support groups with 70 people with mild to moderate AD across the United States, and Brataas, Bjugan, Wille and Hellzen (2010) evaluated with participants with MCI a time-limited day care experience in Norway which focused on a collaborative, person-centred approach to facilitate social and cultural activities. Also in Norway, Helgesen et al. (2010) explored the participation in everyday activities of people diagnosed with mild to severe dementia in specialist residential care.

Proctor (2001) interviewed four women about their experiences within a dementia day hospital, but does not present details of the dementia diagnoses or care. Beyond service evaluation, her work was concerned with the individual's subjective experience of the hospital within the social and political contexts of their lives, particularly in relation to ageing and gender.

Specific care contexts evaluated from the user perspective in the literature include working-age dementia services (Chaston, 2010; Reed, Cantley, Clarke & Stanley, 2002); group living in the Netherlands (van Zadelhoff, Verbeek, Widdershoven, van Rossum & Abma, 2011); and specific innovations, such as focus groups with PWLD and their families regarding the physical design of care service buildings (Innes, Kelly and Dincarslan, 2011), and the usability of artificially assistive technology to foster engagement in creative occupations (Leuty, Boger, Young, Hoey & Mihailidis, 2013). The latter two demonstrate the value of drawing upon practices outside of traditional health and social care, which rely upon user feedback to design products and services.

1.3.2.2.2. Methods for eliciting user views, and findings

Three studies did not provide empirical data regarding user views, but rather reviewed processes of care and research which facilitate the communication of the user's experience. Forbat (2003) discussed the power dynamics of, and barriers to, understanding the dementia care and research experiences of people from minority ethnic groups, and the complexity of the intersection between minority identities and Western biomedical discourse in regards to stigma and developing a shared language. Forbat positions her reflections as necessary

within a literature of dementia care which is too often silent on the processes of recruiting and gaining access to “‘hidden’ populations” (Forbat, 2003:646). Both Dewing (2007) and Fisk, Beattie and Donnelly (2007) considered the ethics of consent to care and research for PWLD. Both argue that a diagnosis of dementia does not inevitably indicate incapacity to give consent for research involvement; rather, capacity to consent is largely situational and complexity-dependent. This builds upon the MCA (2005), whilst expanding the processes of determining capacity, in that a single act of obtaining consent is inadequate for PWLD, proposing instead consent as a process throughout research. Both also argued for the need to develop research and inclusive and ethical approaches with people with cognitive impairment.

1.3.2.2.2.1 Questionnaires, interviews and focus groups

Snyder et al. (2007) used a questionnaire with a combination of rating scales and open-ended qualitative feedback with support group participants with AD from groups across the United States. The value of learning about living with AD, socialising and improved ability to cope with and accept the diagnosis were the predominant self-reported positive effects of attending the group. The authors pointed to the value of qualitative feedback as a useful indicator of effectiveness of social and educational group interventions, and a guide to the outcomes valued by PWLD. They acknowledged the professional role in determining survey questions, based upon what they considered the ‘clinically observable impact’ of attending the group, which limits the extent to which the agenda of PWLD is heard.

Brataas et al. (2010) undertook qualitative interviews with nine participants with MCI at a Norwegian day care centre. Findings indicated that users had ‘positive experiences’ related to meaningful engagement, collaboration and social fellowship. There were also pragmatic concerns for participants, such as a safe transfer from home to the service. This study particularly highlighted the social role of services for older people with cognitive impairment, and has implications for how we conceptualise dementia care and the consequences of societal responses to dementia. The authors argue that the concerns of PWLD can

usefully be further researched to explore care experiences across and within different contexts, both cross-culturally, and in the context of individual life experiences. Brataas et al. (2010) sought to understand individual interpretations of their accounts, yet focused on shared themes. Subsequently diverse perspectives appear to have been lost, and the authors commented on data saturation with interviews which “provided no new insights” (p.2841).

The uniqueness of individual experiences of dementia and care, and the interactions between neurological impairment, biography/life history and social psychology warrant further exploration, with several researchers attempting to address this complexity. Reid, Ryan and Enderby (2001) also studied day care experiences of PWLD, highlighting that PWLD have “important things to say as service-users if appropriate strategies for listening are employed” (p.377). Via process-consent and interview methods for listening and inclusion, a thematic analysis found that ‘being here’, at the service, was a recurring theme with multiple meanings. For some ‘being here’ related to giving family members a break, for others was unscrutinised, and for others referred to a chance to get out of the house. Whilst the research aim was to consider unmet respite care needs, the findings indicate that PWLD do not have “*a voice* – but instead have individual, articulate *voices* that speak of unique life experiences” (p.389). The authors note that this is rarely acknowledged in the literature, and subsequently in care design, and responding to the ongoing personal lives of PWLD is key to future research and practice. The authors pointed to the difficulties in compromising between stakeholder views, but argued that it is only PWLD who directly experience the services, so their views must have primacy.

The interview and questionnaire-gathered data reviewed in this section is under-theorised by the authors, who tend to list themes, rather than attending more broadly to how PWLD present and construct themselves and their experiences. Consequently the possibilities for others to build upon the research, both theoretically and across care contexts in practice, are limited.

Proctor (2001) demonstrated via unstructured interviews that, regardless of staff opinions about cognitive impairment and ability to participate in research

conversations, the participating women with dementia were able to tell stories - often in fragmented ways - and convey their views on the day hospital. Proctor's qualitative analysis followed Brown and Gilligan's (1992) Voice Relational Method, concerned with the relational and power-related aspects of the stories told. For example, stories were told about experiences of staff withholding care-related information, and of the participants' resistance to powerlessness. This study is limited to four women talking in short (15–30 minute) interviews, in a particular service context. Proctor's chief concern is the power relations of the women's relationships with medical staff, arguably to the neglect of the broader context of the women's individual lives and histories. However, the research usefully points to what may be important to people in receipt of dementia care, and validated their experiences via feedback and service recommendations.

Bamford and Bruce (2000) point to the importance of co-constructing the research agenda and resulting care objectives with those who use care services. The authors highlight the difficulties with professional agenda setting, such as transposing pre-existing outcome measures into a dementia context, which marginalise the voices of PWLD. Therefore, the authors undertook a process of consultation, involving formal and informal groups and interviews with PWLD and carers regarding what outcomes are valued. Whilst there was some overlap between the priorities of PWLD and carers, the desired outcomes were largely in contrast to the outcome measures used by professionals. Users particularly emphasised the value of services which maximise a sense of autonomy. The authors concluded that the processes of care, rather than outcomes, are of most importance to users. They called for future research to focus upon such processes and develop a broader understanding of the aims and objectives of dementia services from the user perspective.

1.3.2.2.2. Observations as an adjunct to direct communication

Helgesen et al. (2010) developed a grounded theory of patient participation based upon observation and conversation with staff and residents in dementia care. They highlighted the importance and complexity of the ways in which professionals are 'present with' PWLD, and the implications for inclusion in day-

to-day care and decision making. This included staff being physically present, being there in mind – such as their competence and knowledge of the individual to communicate in an appropriate way – and ‘being there in morality’, which the authors describe as being fully present, respecting and engendering personhood. The ability and will of the PWLD to participate in interactions was influenced by the professional presence, in addition to the person’s previous care experiences. The authors also considered organisational conditions which enabled staff and residents to be fully present in daily participation, and point to the role of leadership values and service design in stimulating or inhibiting patient participation. This study has ecological validity, and the authors note that contrary to professional assumptions, PWLD can provide reliable data over multiple occasions. Norwegian researchers have produced innovative examples of inclusionary research, which may relate to national priorities in special care units for PWLD; with individualised care and participation in decision making key priorities (Gruneir, Lapane, Miller & Mor, 2008).

Despite the above, Helgesen et al.’s (2010) assertion that observation was necessary to increase the validity of data gathered from conversations can be critiqued from a social constructionist perspective. The methodology denies the validity of subjective experience, and points to a realist epistemology wherein there is an ‘experience of dementia care’ which can be objectively observed by a researcher. The authors highlight the concern that PWLD may offer unreliable opinions, but do not question whether this would be true of anyone, with each research encounter a particular context for talk and behaviour (Beresford & Evans, 1999). The research can also be ethically critiqued in regards to the assumed incapacity, and subsequent exclusion from research conversations, of people based on the severity of dementia diagnoses.

1.3.2.2.2.3. A multiplicity of perspectives

De Boer et al.’s (2007) review of the international literature on the experience of dementia concluded, perhaps unsurprisingly, that PWLD offer a range of subjective views on care preferences. For example, some value day care, some find such services under-stimulating; the primary concern for some is their safety,

and for some reminders of loss is a negative consequence of care services. The authors conclude that viewing user perspectives on dementia care as diverse “provides a good starting point for further studies into the adjustment of care to the subjective needs and wishes of people with dementia” (de Boer et al., 2007:1036). However, there is a gap in understanding the factors that contribute to these needs and wishes, such as life histories and social context. Also, Reed et al.’s (2002) service evaluation via interviews, and secondary data such as care records, with people of working age diagnosed with dementia, highlighted the need for services that are responsive to individual needs, rather than ‘age-specific’ needs. This was in contrast to concerns voiced by staff that services be age-appropriate. The authors concluded that services responsive to individual needs warrant further attention across client groups. Similarly, van Zadelhoff et al. (2011) found from observations and interviews with staff, user and carers regarding experiences of group home living in the Netherlands, that the operationalised values of attentiveness and responsiveness to individuals’ needs were viewed as most important to enable good professional care. They argued that group homes with a homelike atmosphere and small number of residents can create conditions to facilitate these values, but that broad agendas (e.g. fostering autonomy) may interfere; for example, where many residents may find meaning in daily chores, some residents may not wish to undertake duties such as table-setting, “having done this kind of work long enough” (van Zadelhoff et al., 2011:2494).

Asquith’s (2013) interpretive phenomenological analysis of interviews with dementia service providers and users in Kent demonstrates the limitations of attempting to draw themes across the talk of individuals in the absence of contextualising both each individual (e.g. within their life experiences) and the research encounter. The analysis constituted a summary of what appear to be opinions, rather than experiences, from which Asquith concluded that providers and users had the same understandings of what is valued in dementia care, for example peer support and personalised services. Limited methodological detail regarding the interview-schedule, and the extent to which participants could bring their own agenda, has implications for any conclusions drawn. Furthermore, in the context of a dementia care literature that broadly fails to operationalise key

concepts such as ‘person-centred’ (Epp, 2003), research such as Asquith’s does little to move the agenda forward into practice. As a useful adjunct to the above, Asquith, Guss and Oliver (2013) used an in-depth case study to evaluate one service user’s experience over one year. Subsequently, key themes such as the value of relationships, were used to inform service guidelines locally.

Interestingly, contrary to professional assumptions that PWLD are unable to give their views, studies such as Innes et al.’s (2011) found that despite asking focused questions (e.g., regarding the design of buildings), PWLD were able and willing to share the complexity of their concerns, such as those regarding the life they would be able to lead within the proposed support systems and the importance of choice. Innes and colleagues again pointed to the diversity of the values and wishes of PWLD, and the importance of designing services which respond to each individual.

1.3.2.2.4 Beyond listening

Dupuis, Gillies, Carson, Whyte, Genoe, Loiselle and Sadler (2012) developed the notion of ‘inclusion’ into one of partnership with PWLD, drawing upon theoretical approaches to working *with* people, recognising how they have been silenced and excluded, whilst also recognising the collective capacity for empowerment drawn from critical pedagogy (e.g., Freire, 1970). In particular, their ‘authentic partnership model’ challenges the dominance of professional knowledge and acknowledges the value of experiential knowledge. They argued for moving beyond listening to PWLD to active and meaningful involvement in decision-making. Their partnership projects between PWLD, family members and professionals demonstrate that, with support, PWLD can hold active decision-making roles. The partnerships included forums developed around topics of interest to PWLD, such as sharing information about living with dementia in a range of media including songs, drama and art. The processes of collaboration were analysed qualitatively, finding that ‘authentic partnerships’ include and value diverse perspectives across stakeholders, and enhance the ‘humanness’ of each through reciprocity and valuing interdependence. The authors call for further collaborative research and care practices for PWLD and the valuing of diverse

perspectives. Dupuis and colleagues focused upon local partnerships, in Toronto, Ontario, and argue for others to develop the model of collaboration in their local contexts. Key decision-making and planning roles were held by people with early-stage dementia, who were then concerned with making the initiatives accessible to all with dementia. Details about participants are brief in their write-up, and it is difficult to ascertain whether full partnership rights were accorded to people with more severe dementia diagnoses.

A UK example of partnership, the Healthy Living Club in Lambeth, South London, draws upon co-production in social care. People with and without dementia labels run services, such as a self-directed social club, together, supported by strong links with the local community. The partners have produced advice for others on how to undertake co-production of services, such as by drawing on local and professional resources and using social media to raise awareness of projects (Social Care Institute for Excellence, (SCIE) 2013a).

As in the above example, beyond peer-reviewed and academic literature there are examples of the inclusion of PWLD in developing specific initiatives and care practices. This literature review cannot comprehensively reflect the ever-changing policy and practice landscape, but rather is a broad snapshot in time, with evidence selected and reviewed in late 2013.

1.4. Why is knowledge of user experience important?

It is, of course, not novel to suggest that PWLD could have a role in shaping care practice (Audit Commission, 2000; Reid et al. 2001). Reid et al. (2001) highlighted over a decade ago the growing interest in the role of users of dementia services in health and social care service development, supported by a focus on user experience in academic discourses (Cotrell & Schulz, 1993; Lyman, 1989). Such agendas related to wider moves in health and social policy to shift focus from “pathology to people” (Reid et al., 2001:377) and the emergence of policy narratives such as ‘service users’ and ‘consumer choice’ (DoH, 1990). Current UK dementia policy commits to offering PWLD and their carers the opportunity to participate in high quality research, noting that in

comparison with other conditions, such as cancer, the level of public engagement in research is low (DoH, 2012). However, the policy does not outline what might constitute meaningful participation, and the recommendations primarily relate to advancing biomedical research and disease prevention (DoH, 2012).

Dupuis et al. (2012) note that dominant approaches to dementia research and practice emphasise a professional and 'expert' knowledge base, including the elevation of the voice of family carers, to 'expert status'. They argue that 'person-centred care' often places PWLD 'at the centre' of care decisions made by others, but that PWLD are not central to the process of decision-making. This is echoed in broader concerns regarding patient leadership in UK healthcare. A recent conference report from the Centre for Patient Leadership (Gilbert, 2013) warned against a rhetoric of participation in the absence of meaningful ways to participate and collaborate in practice. In the context of challenges in the UK to manage growing health demands within a shrinking welfare system, Gilbert argues that there is potential for patients to become part of the solution via meaningful collaboration, or indeed leadership.

Beyond professional dementia 'experts' there is broader evidence of champions for the centrality of the views of people to whom dementia research, policy and care refers. For example, Hepburn (2013), a member of the DoH communications team, recently urged policy makers to listen to the views of PWLD online. Whilst going online might not be practicable or desirable to all, there is evidence of creativity in eliciting the views of PWLD outside academic literature. For example, writer John Killick (1997) works with PWLD to create poetic representations of their experiences. Killick describes the metaphoric use of language by PWLD to communicate their emotions and experiences.

Rose (2008), a service-user and professional mental health services researcher, argues that there are epistemological and political reasons for the traditional privileging of professionally, and largely medically, led quantitative research in academic literature, over service-user produced research and a broader range of methods to understand user experiences:

Service user produced knowledge – or “evidence” – uses different methods to mainstream research and consequently produces a different view of the world of mental health. Mainstream researchers need to look at this seriously and not dismiss it with broad and less than serious arguments. It is my view that to resolve such issues we should pay attention to the different epistemologies that underlie the fractures between mainstream and service user research. (Rose, 2008:451).

Miller and McClelland (2006) point to the potential effects of the empowerment of currently poorly resourced groups such as service users, in a limited resource environment such as the NHS, i.e., the implied disempowerment of powerful others. Is it therefore politically expedient to address the concerns of service users? A recent review of the status of user leadership and participation of PWLD suggests that it could be: “on the basis of what people with dementia have said as part of [*the review*] it also seems reasonable to assert that the recent ‘challenges’ on dementia announced by Prime Minister David Cameron cannot be addressed and overcome without the active involvement of PWLD in both the methods used and evaluation of success” (Williamson, 2012:72).

1.5. Moving towards meaningful inclusion?

Wilkinson (2002) drew upon Sabat’s (1998) work on engendering personhood by listening to PWLD, and the moral and ethical foundations to dementia research (e.g. Post, 1998), to argue that inclusionary research is essential for the development of services that are ethical and meet the needs of individuals. The literature reviewed above illuminates the unfortunately limited progress in inclusionary dementia care research in the decade since Wilkinson made the case for it. Questions remain as to how we practicably and meaningfully include the perspectives of PWLD, and understand and respond to their experiences.

Bartlett and O’Connor (2007) draw upon the discourses of citizenship and inclusion to argue for a citizenship model of dementia that expands the focus from individual to political, encompassing issues such as social inclusion, power,

rights and personal agency. Beresford (2002) outlines how concern with democracy, rights and empowerment contribute to a progressive form of user involvement in comparison to those based upon narratives of consumerism, i.e., seeking user input to increase service efficiency. A citizenship model is congruent with the mental health service 'survivors' movement, which politicises the user's position within the context of services and society more broadly (Wallcraft, Read & Sweeney, 2003). Baldwin (2008) outlines a theoretical approach, whereby citizenship is demonstrated and co-constructed through the stories told by and about us, across personal, interpersonal and institutional/structural contexts.

Despite the interest in developing user involvement in dementia care, the stories of PWLD have historically seldom been heard as part of the policy and service development process (Robson, Sampson, Dime, Hernandez & Litherland, 2008). The high proportion of studies in the literature review that did not meet the criteria for inclusionary dementia care research suggests both an acceptance of, and contribution to, professional assumptions that the effects of cognitive impairment, and an assumed lack of capacity to be involved in decision making, are prohibitive to inclusion (Hernandez et al. 2010; Dupuis et al., 2012). This is contrary to policy agendas regarding user feedback on services (e.g. DoH, 1990) and the aims of the MCA (2005) to support people to make their own decisions, with an assumption of capacity to do so unless all practical steps to aid decision-making have been unsuccessful.

However, Williamson's (2012) review concluded that the 'movement' for user participation and leadership for PWLD is in its infancy. The review stated that PWLD welcomed support from professionals in developing the movement, provided that the agenda was led by users themselves, who remain the experts in their experiences. The World Health Organization and Alzheimer's Disease International (2012) further identify how alongside this 'knowledge gap' in what is known about what PWLD want from care, there is an 'action gap' between knowledge and concrete steps to implementation.

1.6. Conclusions from the literature review

The review of the current status of representations of user views in dementia care research points to a gap, particularly within academic research, where the experiences of PWLD remain seldom heard, and the diversity of their perspectives under-theorised and de-politicised. Research methodologies which consider the experiences of service users as central are under-represented, in comparison to those which prioritise professional or other stakeholder agendas. The evidence indicates the value of developing inclusive methodologies in dementia research and collaboration with PWLD to inform the development of dementia care. Beyond simply evaluating services (an area of research which has to some extent evidenced user inclusion) there is a gap in what is known about how individual life experiences and the broader socio-political context relate to the care experiences of PWLD, and how sense is made of these experiences. Developing a theoretical basis for this, with particular attention to process as well as outcome, could strengthen the position of user perspectives in academic literature.

The under-representation of user research and inclusive methodologies is also seen in the mental health services research literature (e.g. Rose, 2008). This gap is concerning on moral grounds, in that it subjugates the voices of already marginalised groups, but also pragmatically, in that we currently lack the knowledge to develop services which respond to users' self-defined needs. In a dementia context this is ultimately likely to increase the so-called 'burden' of caring for an ageing population. Fox et al. (2013) outline the potential harm from raising dementia awareness and screening in an ageing population, in the absence of a strategic approach to research to determine where it will provide tangible benefits to the population. Amongst other things, this requires increased knowledge about what are meaningful dementia care services that meet the needs of PWLD. Fox and colleagues in particular call for independently evaluated, rigorous research to inform the inevitable reorganisation of healthcare for an ageing population. The BPS (2008) highlight the potential role of CPs in advancing dementia research knowledge and service development.

1.7. Research Aims and Questions

The approach adopted in the current research to meaningfully listen to the perspectives of PWLD is a response to Baldwin's (2008:224) contention that the inter-relationships between the personal, interpersonal and the institutional/structural are co-constructed and demonstrated "through the stories we tell and are told about us, whether by individuals or collectivities (such as the Law, businesses and government)". The current research aimed to elicit and analyse narrative accounts by PWLD regarding their professional care experiences. The research is intended to inhabit a position which responds to Baldwin's (2008) call for empirical work to facilitate the link between personal and public policy narratives and Rogers and Pilgrim's (2010) sociological perspective which points to the value of widening the sources of information available for policy-making to include the course and meaning of individual experiences.

The aim of such research is "to understand something of each individual's perspective" (Proctor 2001:361) and of the interaction between individual and public narratives. Beyond these aims, this research recognises that "People with dementia may tell us something about what it means to be a human being, beyond our accepted cognitive definition" (Barnett, 2000:26), and aims to contribute to the development of alternative research methodologies in dementia care to facilitate users' participation. Wilkinson (2002) argues that such research is an important step towards a policy context, and therefore services, for PWLD that is both based on, and responsive to, personal needs and experience.

Including, yet moving beyond, seeking user feedback (an area under-represented in relation to older adults in general and PWLD in particular) the research questions aim to address the political concerns outlined in the introduction and the lack of conceptual clarity as to the processes of care in a dementia context. For example, *how* PWLD position themselves in their stories of care is attended to as a potential demonstration of the politics of care, and the possibilities and limitations for action and identity constructions within the current UK context. The questions of *what* stories are told, and care valued, aim to elicit the information we currently lack to make sense of what dementia care is ostensibly for, from the

perspectives of PWLD, and which, if any, of the breadth of possible factors outlined, matter to them. If the theoretical basis currently lacks sufficient clarity to inform coherent provision, asking PWLD themselves can offer the expertise to guide it.

The broad research questions developed to address these aims are:

- What stories of professional care do PWLD tell?
- Within this telling, how do people position themselves through the narratives told, and how do they make sense of care experiences?
- What are the implications in relation to what care they value or would value?

2. METHOD

This chapter outlines the rationale and method for a narrative approach to analysing the accounts of PWLD, and details the methodology and procedures for recruitment and data collection.

2.1. Why Narrative?

Killick (2001) suggests that direct and structured questioning with PWLD can lead to anxiety and confusion, suggesting instead time and encouragement to ‘tease out’ perspectives which may be represented in narrative form. Narrative research, in the form of unstructured interviews and groups with PWLD regarding their experiences of professional care, was the approach designed to meet the research aims.

Narrative can broadly be defined in this context as an account of experiences or events, singular, habitual or hypothetical, “perceived by the speaker as important [...] selected, organized, connected and evaluated as meaningful for a particular audience” (Riessman, 2008:3). Narrative analysis takes a multitude of forms and approaches, and in the present study the approach moves away from definitions of storytelling that focus upon structural and sequential features. As a

consequence of the impairment in language and cognitive function associated with dementia, and the potential decrease in social interaction and marginalisation experienced by PWLD, a threat is posed to narrative abilities (Baldwin, 2006). However, Baldwin (2006) contends that narrow conceptions of narration which focus on structural coherence exclude PWLD, who are commonly viewed as having “lost the plot” (pp. 105). He points instead to the value of co-construction of narratives between people with and without dementia, piecing together seemingly fragmented narratives into a meaningful whole. I have followed Riessman’s (2008) guidance to select an approach to narrative analysis in accordance with the research aims, while being mindful of the features of dementia which may impact on structural aspects of storytelling.

2.1.1. A social constructionist approach to narrative

The research aims point to a social constructionist epistemology, concerned with the processes by which stories are told to describe, explain and account for oneself and the world; both being created by, and co-creating our experiences and identities (Burr, 2003). The analysis attended to the constructive role of public narratives for the identity and care experiences of those labelled with dementia. Additionally, regardless of the extent of cognitive impairment (Clark-McGhee & Castro, 2013), micro co-construction of personal accounts and identities occurs, and was analysed, within interpersonal interactions.

2.1.2. An integrated approach to analyse narratives in context

I adapted Stephens and Breheny’s (2013) integrated approach to narrative analysis to re-tell and interpret the individual and collective narratives told within the immediate context of the research encounter, and the broader socio-political context. Emerson and Frosh (2009) argue that to isolate an individual story from its context reduces its meaning, a concern I balanced with retaining the narrator’s voice, particularly important for persons potentially subject to repressive societal narratives (Murray, 2003).

2.1.2.1. Key Narratives

The analysis of narratives in context required initially the identification of each person's 'key narratives', or in a group context the key individual and/or collective narratives. Phoenix (2008) defines these as the key themes which organise how story(ies) are told, often identified by repeated content across stories told in an encounter. This relates not necessarily to stories of events, but more broadly may be habitual or hypothetical stories. Boenisch-Brednich (2002) points to the development of these key narratives in the context of people's life histories, and Phoenix (2008:67) highlights how these may have been repeatedly told and subsequently become 'well-worn accounts that are used to explain and justify people's actions and decisions'. Congruent with narrative in the context of dementia research, the approach de-emphasises structural aspects of story-telling and is instead concerned with accounts that construct people's values, roles, feelings, personal philosophies, etc. My analysis of key narratives was concerned both with particular accounts of professional dementia care, alongside stories about people's broader experiences that contribute to their sense-making in regards to care experiences. Given that key narratives may be embedded across personal accounts within different sorts of stories, identifying them required repeated re-reading of each interview or group in its entirety.

2.1.2.2. Analysis at the positional and ideological level

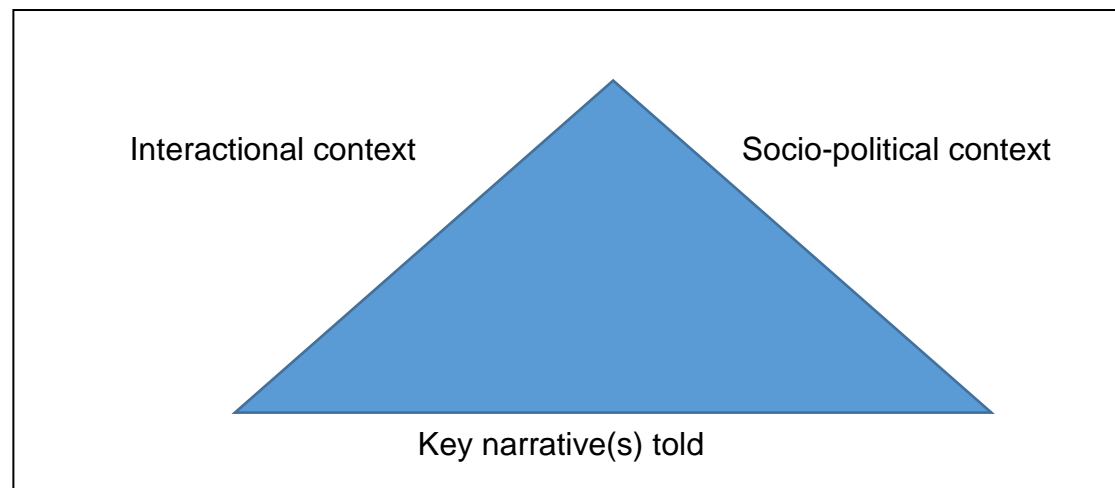
Attending to the positional level of storytelling engenders understanding of the wider context, the social and moral function of public narratives and practices employed in interpersonal interactions, and the subject positions and power relations involved in the co-construction of identity and experience (Stephens & Breheny, 2013).

For narrative analysis at this level I drew upon Phoenix's (2008) notion of 'establishing an entitlement to talk', and its relation to identity claims. For example, this may refer to how people use membership of a particular social group (e.g. 'old' or 'with dementia') to claim authority to speak on a subject or, conversely, to deny entitlement to speak. Positioning is fluid, and van

Langenhove and Harré (1999) distinguish between the 'self' of personal identity, i.e., an enduring worldview which drives one's actions and enables a sense of personal agency, and the 'personae', i.e. discursively and publicly produced identity. To analyse these processes I followed Baldwin's (2006:107) suggestion to attend to "'small stories', stories that privilege the fleeting and fragmented as contributing to the performance of identity in everyday interactions". The "local assignment of rights and duties" through positioning acts relates to the macro-structures and practices within which these positions are concretely realised (Harré, Moghaddam, Pilkerton Cairnie, Rothbart & Sabat, 2009:12).

To integrate these levels I combined and adapted Stephens and Breheney's (2013) and Harré et al.'s (2009) analytic approaches, representing the interplay between personal stories told, interactional relationships between narrator and audience and broader socio-political contexts (summarised in Figure 1). The integration of personal and social stories attends to the cultural rules which influence the narratives people tell (Stephens & Breheney, 2013). As Harré et al. (2009) outline, the act of prepositioning, i.e. establishing the 'character' and/or competence of a speaker, provides a foundation to an interaction, upon which possibilities and limitations are assigned to or taken up by a speaker. These possibilities are particular to the interactional (the research encounter) and socio-cultural context. The latter can be thought of as a larger interactive episode which generates a number of broad classes of storylines, or 'frames' and more specific cultural storylines (Goffman, 1986) within which interactional acts are interpreted. For example, commonly drawn upon storylines in the UK and US at present include the national crises of an ageing population (Hilton, 2010), the 'good mother' (Stephens & Breheney, 2013) and redemption as a transformation of suffering (McAdams, 2006). As Figure 1 summarises, the social psychological dynamics analysed are concerned with the effects of context upon which stories may be told in an interaction, whilst also the telling of a story may constitute an act of (re)positioning, drawing upon alternative cultural frames associated with different possibilities and limitations in an interaction. This analytic approach is not step-wise, and each interview and group encounter transcript was analysed separately. Appendix 2 presents a sample transcript excerpt which demonstrates my application of the analytic process built over re-readings.

Figure 1. Diagrammatic summary of approach to analysis



2.2. Consultation with PWLD

In response to the poor record of inclusive dementia care research indicated in the literature review I aimed to include PWLD in the research design.

Consultation with PWLD, via an inner-London AS branch, is summarised in Appendix 3.

2.3. Data collection

The impact of each individual's cognitive ability and the 'negotiated social relations' between researcher and researched to ensure ethical participation are two key considerations in research with PWLD (Wilkinson, 2002). The aim of data collection in the present research was to elicit narrative accounts from PWLD regarding their experiences of professional care. The proposed methodology draws from examples of good practice and feedback from consultants with dementia.

2.3.1. Rationale for groups and one-to-one interviews

Based upon the consultants' advice, data collection comprised a combination of group conversations and one-to-one interviews, both of which have been successfully utilised in previous dementia research. Whilst naturally occurring groups produce ecologically valid communication and reduce the power

differential between researcher and researched, interviews offer space for lengthier narrative expression (e.g., Hernandez et al., 2010; Hubbard, Downs & Tester, 2003).

2.3.2. Procedure

Participants were recruited to either the group or interviews, none of whom had participated in the consultation. Both the one-to-one and group conversations comprised unstructured conversations following a uniform opening question to elicit the stories of participants in relation to professional care. Based upon the research questions, the consultants suggested a relevant and understandable opening question:

‘Can you tell me about a time when you have received care from staff?’

As in Montague’s (2005) research of relationships in talk amongst older women, it was intended that each conversation assume its own pattern. I undertook a pilot to develop prompts to elicit narrative accounts with a convenience sample; a pre-existing support group of older adults¹ without labels of dementia at a community mental health team. Initiating a discussion around their experiences of the support group the following were identified as useful to elicit narrative responses:

- prompts, such as “Are there any particular times which stand out?”
- broad questions, such as “Can you tell me about your time here in the group?”
- summarising the talk and leaving space to respond .

This is congruent with Elliott’s (2005) guidance that straightforward, non-technical questions are most effective in eliciting responses in narrative form.

The duration and pacing of the encounters were dictated by the participants, to avoid tiredness and anxiety, informed by each interaction (Clarke & Keady,

¹ This research is not exclusively relevant to older people, although the recruitment strategies adopted in practice selected people over sixty-five.

1996). Additional meetings were offered to both the group and interviewees to enable collection of potentially fragmented 'small' stories over time (Baldwin, 2006).

In total, three group sessions were held, with the same four participants at each, and an additional fifth participant in the first group, with a duration of 39 to 45 minutes each. One-to-one interviews with an additional three participants were conducted, ranging in length from 28 to 58 minutes. None of the one-to-one interviewees opted to meet again to continue the conversation, reporting that they had discussed all they wished to on the topic.

Data collection took place at venues deemed acceptable to participants. The group was held in a private room at the Integrated Day Service recruitment site, and each interview at participants' homes.

Guidelines for good interview and group research practice in dementia care were followed. For instance, Wilkinson (2002) argues that a group is useful when focus upon the research topic is maintained and group interaction generated. This included ensuring each person contributed, for example using prompts such as 'I could see you nodding, is that similar to your experience?'.

The group and interviews were audio-recorded on a digital device and transcribed by the researcher for analysis. Congruent with the approach to analysis I included the complete utterances of both myself and participants in transcription, including false starts, non-verbal sounds, interruptions etc. I intended to represent the research encounter, in which personal narratives were performed for a particular audience, and co-constructed in interaction, whilst preparing readable written accounts for the identification of narratives. Appendix 4 presents the transcription conventions used.

2.4. Participants

2.4.1. Recruitment

PWLD were recruited via an Integrated Day Service (IDS) within an outer London local authority Adult Social Care service, and the same inner London AS branch which hosted the user consultation. The IDS provides long-term places within day care for people diagnosed with dementia. Clients attend for between one to five days per week, with a programme of social and cultural activities, meals and groups such as cognitive stimulation. The stated aim of the service is to help PWLD maintain their wellbeing in the community. The AS service offers a range of support to 'people affected by dementia', such as support groups, social events and advice. Diagnosis is not a prerequisite to accessing support. This is not a comparative study, e.g. across dementia diagnoses or the type of support received; the aim was to consider professional dementia care experiences broadly.

Recommendations for the appropriateness of small sample sizes in dementia research (Cottrell & Schulz, 1993) indicated a small *n* group discussion alongside three to four individual interviews as a suitable basis for data collection.

Having introduced myself and the research to the management teams at both services and at meetings with frontline care staff, staff at the recruitment sites were asked to identify people meeting the inclusion criteria, which initiated the process consent method outlined below.

2.4.2. Inclusion Criteria

Participants were required to be in receipt of dementia care services as the primary service user, i.e., not as a carer of the person with dementia. An ability to express oneself in English was required to enable the researcher, an English speaker, to undertake a thorough narrative analysis of the transcripts.

A particular diagnosis, type of care experience or level of cognitive ability were not a prerequisite for inclusion. Previous research has ethically elicited emotional

memories from people with moderate to severe cognitive impairment (Mills, 1997) and found interpretative and interactional abilities retained alongside cognitive impairment associated with dementia (Wells & Dawson, 2000). However, despite the conversations I had with staff and supporting guidance (Appendix 5), it is difficult to ascertain to what extent staff exercised their own exclusion criteria. Some were openly protective of the people they work with, concerned that trying to understand the concept of research would be distressing, or simply a waste of time. Many of the staff however engaged in dialogue about inclusive approaches, for example, suggesting 'just ask him, he'll soon tell you if he's not interested'.

2.4.3. Participant Demographics

In response to the preferences and facilities of each recruitment site, it was agreed that the IDS service would facilitate recruitment to a group and the voluntary organisation to interviews.

Subsequent to the consent process outlined below, all but one participant consented for the researcher to collect demographic data and data on dementia diagnosis and care pathway (Tables 1 and 2). The research aims do not necessitate attributing professional definitions, such as diagnostics, to the narratives of individual participants. The data is offered at a group level for methodological context. Participants understood that the data would be presented at a group level for general context; I have therefore not attributed participant pseudonyms to specific demographic information for the purposes of anonymity. The aim is primarily to indicate the range of people who participated, particularly the range of diagnostic labels and care needs which may historically have precluded inclusion in research.

Demographics were gathered directly with participants, in some instances during narrative accounts, and with their permission, afterwards in liaison with staff and carers. It was revealing that after the first group discussion I checked with the IDS manager that this was indeed a group of PWLD, as the interactions were, from my experiential position, indistinguishable from that with any other group of older people I have worked with.

2.4.3.1. Group participants

Following guidance to staff at the IDS to identify four to six PWLD for a group, five people out of sixty were identified as meeting the inclusion criteria and all five consented to participate. One of the five participants attended only the first group as she was absent from the IDS on the subsequent dates due to family commitments.

Table 1. Demographics for group discussion participants

Age	Gender	Ethnicity	Dementia Diagnosis	Care Pathway
78	Female	White British	Diagnosed approximately nine years ago with AD	Attends IDS three days per week, for previous nine years. Family support and biannual medical review.
91	Male	White British	MCI diagnosis	Attends IDS two days per week, no family support, lives in sheltered accommodation.
74	Male	White British	Dementia with Lewy bodies, diagnosed approximately three years ago.	Attends IDS two days per week. Wife is main carer, with voluntary carer at home weekly for respite. Medication. Multidisciplinary team (MDT) input, including social care.
87	Male	White British	MCI	Attends IDS three days per week. Self-care, with biannual medical review.
70	Female	Asian British-Pakistani	MCI diagnosed three years ago, recently progressed to 'Early mixed dementia'.	Attends IDS two days per week, for previous three years. Family support and self-care.

2.4.3.2. Interview participants

All four people identified as meeting the inclusion criteria by staff at the AS, selected from a population of approximately 500 service users (excluding carers), consented to participate in the interviews. One potential participant experienced unexpected housing problems and subsequently declined to participate. Of the three participants, two consented to the collection of demographic data. The third participant had discussed concerns during the consent process and the interview that her responses be directly linked to the care she receives. Having experienced recent cuts to services, she was fearful that her support could further be reduced. I judged that to follow the interview by making a request for details of her care would cause unjustifiable anxiety and confuse the purpose of her participation, which she had understood as giving anonymous opinions of her experiences. Her demographic data is included only in regards to that she discussed herself during the interview.

Table 2. Demographics for interview participants

Age	Gender	Ethnicity	Dementia Diagnosis	Care Pathway
84	Male	White British	Diagnosed with AD approximately two years ago	Voluntary sector social group monthly. Medication. Self-care.
74	Male	White Irish	Diagnosed with Parkinson's Disease two years ago and related dementia six-twelve months ago.	Quarterly neurological and memory reviews. Care-coordinator from community health service. Lives in sheltered accommodation. Previously attended voluntary sector social groups.
86	Female	White British	No formal data collected. Referred to "memory problems" and identified by staff as 'person with dementia' as per inclusion criteria.	Reviewed regularly at a memory clinic, personal care support at home and attends various social support groups.

2.5. Ethical considerations

McKeown, Clarke, Ingleton and Repper (2010) reviewed examples of good practice in dementia research and offer guidance on how to actively involve PWLD within an ethical framework. The authors recommend process consent methods, whilst the MCA (2005) provides a guiding framework.

2.5.1. Informed consent

The processes outlined here are congruent with the aims of the MCA (2005) to aid people to make their own decisions. McKeown et al. (2010) argue that traditional consent approaches, such as obtaining proxy consent and cognitive-competency based approaches, do not respect the perspectives of PWLD and exclude people with cognitive impairment. A diagnosis of dementia does not necessarily indicate incapacity to consent to research involvement; capacity to

consent is largely situational and complexity dependent (Dewing, 2007; MCA, 2005). Congruent with the centrality of the perspectives of PWLD to the research aims, my primary concern in regards to ethics was that each participant be positioned as central to determining their own involvement with this research, within appropriate relational contexts. In acknowledging the complexity of balancing rights (e.g. to give one's opinion, to inclusion) with protection (e.g. from misuse of professional power or loss of privacy) I adopted a process of consent, alongside the unstructured approach to narrative interviewing to enable participants to lead the conversation(s).

Central to the process consent method is the recognition that obtaining consent is a continuous process, informed by verbal and behavioural feedback from the PWLD (Dewing, 2007). This is evidenced here by taking up Cowdell's (2008) recommendation to record these processes in a field diary to provide an 'audit trail' of decisions made and actions taken. To aid transparency, an example field diary is presented in Appendix 6. Appendix 7 details the process of assessing and recording consent to participate throughout data collection, and indeed afterwards, in regards to use of the data for analysis, inclusion in the report and whether he or she wished to make contribution to, or receive feedback from, the analysis.

Of the eight participants, six were considered by staff to be able to give consent themselves. The other two participants usually consented to care decisions with input from their carers. In accordance with the processes outlined in Appendix 7, both carers were approached before approaching the person with dementia and provided with an information sheet for relatives (example in Appendix 8). The purpose was to learn more about how their relatives usually demonstrated their decisions and consent, and to check whether approaching them would be likely to cause any distress. Both carers were clear, verbally and for one carer confirmed in writing using the optional form for relatives (Appendix 8) that it was up to their relative whether they wanted to be involved, and recommended direct discussion with them. Had the carers vetoed the involvement of their relatives, this would constitute a form of proxy consent. This reflects the inadequacies in current approaches to capacity and consent in dementia research, where

researchers must balance the safety of participants with attempting to develop approaches to include traditionally marginalised groups in research. For the remaining six participants, I worked with staff to understand the usual ways the person would communicate consent or non-consent and recorded evidence of such in the field diaries.

The recognition that both decision-making in general, and the cognitive and functional impairments associated with dementia, are contextual, guided the development of consent as a process across contexts (e.g. time and method of information giving). The ongoing negotiation of tensions between ethical practice and pragmatism was recorded in the field diaries and reflects the dilemmas within the research processes. For example, initial discussions with staff about who 'usually' consents for themselves indicated difficulty in distinguishing legally formalised relationships from day to day relational processes. Our discussions distinguished next of kin arrangements with distant relatives who do not know the participant well, from the more relevant informal day to day relationships with staff, friends or family who regularly support individuals in their decision-making. The nature of 'usual' decision-making is also of course extremely variable, for example one participant's wife made decisions related to medication on his behalf, but day to day decisions regarding involvement in activities were made by him alone. It is not immediately clear whether participation in research is more akin to the former or latter, and discussion with both him and his wife clarified that from their perspective it was a decision he could make alone. Ongoing discussions with staff, family and the participants, whilst time-consuming, demonstrated the possibilities of making 'person-centred' decisions where the person is *at the centre of the process*, as opposed to simply held in mind whilst decisions are made about them by others. A process model encouraged formal reflection upon these complexities, relevant to both care and research related decision making, and the development of ethical decision making within the guidance of the MCA (2005).

With the above in place, I met the potential participants individually to undertake a non-hurried consent meeting, using the accessible illustrative information sheet approved by the consultants (example in Appendix 8). The information was

verbally explained, and consent to participation elicited verbally and behaviourally, and evidenced in the field diary. This is an alternative to seeking written consent from the participant which may be unreliable, and in a dementia context potentially anxiety-provoking – people may remember signing an official form, but not recall why (Allan, 2001). Of eight participants identified as suitable for inclusion, all eight verbally consented to participate. Again, questions are raised as to whether staff acted as gatekeepers to avoid selecting people with more complex communication needs, which may have raised questions as to capacity to consent, or who were less amenable to professional requests for participation.

2.5.2. Ethical Approval

Ethical approval was sought and granted from the University of East London Research Ethics Committee (REC) (Appendix 8). In accordance with the relevant current National Research Ethics Service guidelines (SCIE, 2013b), and confirmed in personal communication with the national Social Care REC co-ordinator (April, 2013) no further ethical approval was required to recruit participants from both the AS and the IDS.

In addition to formal ethical approval, local management approval was granted for both recruitment sites. Recruitment and data collection was supervised by an NHS-employed Consultant Clinical Psychologist and the Director of Studies, a qualified Clinical Psychologist, via discussion and review of the anonymised field diaries.

2.5.3. Confidentiality, anonymity and protection of participants

All information was stored in accordance with the Data Protection Act (1998)². All transcripts and field notes were fully anonymised, including names and any identifying details. Anonymity was maintained by assigning each participant a confidential code to manage the procedures outlined above. Codes, and the one

² Digital records, stored on a password-protected computer and deleted from the recording device, were available only to the researcher, and will be erased upon conclusion of examination of the research. Anonymised transcripts will be held by the researcher for a period of up to 5 years to enable subsequent preparation of the research findings for publication.

form for relatives completed, were kept in a locked cabinet at the collaborating sites, separate from the data collected, and will be destroyed following final participant involvement via feedback from analysis. Access to anonymised transcripts was limited to the researcher, supervisors, and examiners.

There are no potential risks identified to participants beyond tiredness, anxiety or confusion, which are addressed in the procedures outlined above and in the appendices, alongside local safety procedures in regards to any indications of risk of harm to participants or others arising during the research processes.

3. ANALYSIS AND DISCUSSION

This chapter details the integrated narrative analysis performed with the three individual interview and three group session transcripts. Aspects of the discussion are integral to the analysis, which attends to the effects of the research context and the broader socio-political context of dementia care outlined in the literature review.

The integrated framework for analysis usefully enabled an exploratory and interpretive approach, responsive to the data. These were important concerns in the dementia context - a previously under researched area, giving rise at times to fragmented accounts. The analysis in practice presented tensions in working from different theoretical and epistemological lenses. I broadly interpreted the participants' accounts as co-constructed in the research encounter, for example how what participants said indicated moves between a range of positions (e.g. cared for, researched, experienced), contextualised within available cultural storylines. At times however, perhaps as a consequence of my being situated during data collection within the IDS and AS service contexts (meeting with staff teams, undertaking the consent processes etc.), I shifted from purely social constructionist towards realist descriptions. This refers to where participants' comments, for example in relation to the 'love' shown by staff (Mrs Kalil, Group 1, Line 12), or social isolation, were interpreted as more 'factual' descriptions of experiences. Further, my experience of the research encounters, combined with psychoanalytic perspectives raised in the introduction in relation to existential

anxieties, pointed to the value of attending to implied and untold stories. Whilst other approaches to analysis, such as discourse analysis, might eschew readings of implicit motivations, in attending to ‘small stories’ told in the context of a whole encounter, narrative analysis enabled interpretation beyond what was said, to consider possibly unconscious processes such as a speaker’s defence against undesirable identities (Holloway & Jefferson, 2000; Phoenix 2008). My concern to make a meaningful whole from each individual and group account, and responsiveness to each, indicated the value of this breadth of theoretical frameworks, even when not purely social constructionist. As Phoenix (2008) argues, such breadth in narrative analysis enables insights into the troubled subject positions, dilemmas and implicit associations between ideas that the story-teller negotiates.

Excerpts presented in the analyses adhere to the transcript conventions outlined in Appendix 4. Where relevant to the analysis, particularly in regards to positioning, interviewer speech is presented alongside the participant. Where interjections such as short utterances of encouragement, e.g. ‘uh-huh’ or ‘yeah’ break the flow of the narrative these have been removed for presentation and replaced with ‘...’.

Brief biographical portraits of each participant are presented in Appendix 9.

3.1. Mick: “No no, I say ‘no no’”

The narrative analysis of Mick’s account is centred around a key narrative of his continuing struggle for personal agency and resistance against people ‘taking advantage’ of him. The research encounter was characterized by Mick’s use of everyday language to describe himself and resist formal medicalised representations, alongside self-positioning as superior to care staff who ‘haven’t got it mentally’ [14]. However, discourses concretely realised in health and social care and the law to some extent conferred a negative, passive identity and engendered Mick’s self-silencing.

3.1.1. 'It's turned me': A past and present struggle against people taking 'mean advantage'

Mick's stories were strikingly organized throughout our encounter around a lifelong struggle to survive, maintain personal agency and resist threats to subjugate, abuse and render him vulnerable.

[550–557] People are not interested in you, cos you've a problem ... You're isolated ... And then, this is why they start ranting and raging and roaring ... for attention ... and erm [2] and you know um I like to, I like to have a social life, I like er, I like at the weekends I get to the Sunday papers, the Catholic papers ... or Anglican papers and pick out all the free recitals.

However, Mick acknowledges the reduced occupation which accompanies ageing, in comparison to his working-age life:

[587–592] I never drew the dole or unemployment, never had to ... I always had work ... and erm that's what I'm used to.

Tessa: ... to be around other people <Mick: yeah> and busy, yeah. And it sounds like, from what you're saying, it doesn't feel like there's chances, opportunities <Mick: No, no> to do that.

Mick: No, I'm an old man now.

In remembering his ability to find work throughout his life, Mick strengthens his current sense of agency to resist the effects of reduced opportunities. Andrews (2014) argues that in storytelling the connections between memories, experiences and the imagined expand the possibilities for meaning-making and action. Such connections are particularly vivid in a dementia context, where temporal and structural coherence is often reduced or absent, enabling, for example, narrating the remembered to make sense of a perhaps bewildering or undesirable present.

Although Mick evidently endeavours to overcome his reduced opportunities, in common with many others, he conveys a fear of loss of autonomy and inadequate care (de Boer et al., 2007). Mick was concerned throughout with mistreatment by, and mistrust of, powerful others:

[33–34] But people that have got problems, there are people erm, using them abusing them.

[509–512] I'm not getting the factualities of problems ... nobody's coming to to advise me.

Tessa: Oh, I see, so you don't feel like you're having things explained properly?

Mick: Yeah yeah yeah, and people are taking advantage of that, mean advantage.

Congruent with Boenisch-Brednich's (2002) observation, this key narrative appears to have developed in the context of Mick's life history. The excerpt below demonstrates both how Mick was abused in childhood by his mother, and how he narrates his family history as one in which he stood up for himself and has overcome and survived, or 'lived on', the literal meaning in French of 'survivre' (Derrida, 1979), as the only remaining living family member:

[749–760] She battered me every day and night, and the day, and the day my father was buried I walked out of the cemetery ... [2] Made sure I was made notice. My father had a magnificent funeral ... but she said she started scrimping off of it and the day, the last time I saw her [2] um [2] um the last time I saw her alive [1] she was dying ... And I said 'I'll never forgive you ... you made everything for my sister' ... and [2] and every one of them has gone to their rest ... I'm the last one alive

Tessa: Yeah. [3] How does that feel?

Mick: Well it doesn't worry me ... cos I've rid of the evil.

Mick's narrative of leaving behind his abuser, and making her aware that she is unforgiven, suggests a sense of personal agency and self-protection necessary

for survival. I did not interview Mick explicitly about his life story; the above suddenly followed Mick's talk about a newspaper article he had recently read about AD 'destroying homes' [733]. His telling of his family story appeared linked by a past and current threat to his personhood: in the past through limited family support and 'evil', and in the present through recently leaving his home for sheltered housing, ageing and getting 'forgetful' [480]. The central concern to maintain personal agency is congruent with previous research which emphasises the value of care processes which maximise a sense of autonomy (Bamford & Bruce, 2000) and the role of others in enabling personhood through relational processes founded upon respect and trust (Kitwood, 1997).

In the context of threats to self, Mick's authorship of his identity appeared conflicted as he attempted to narrate who he is, or needs to be to stay safe:

[430] Well, I've only started this, er, I have a reputation of being a bit soft.

[491–499] Tessa: Do you feel that people are taking advantage of the fact that you have these difficulties [*being forgetful*]?

Mick: I don't know, no no no. The difficulties with me are I'm generously, I've a generous streak in me.

Tessa: So what you said about being, having a reputation about being soft.

Mick: Yeah ... but that's stopped.

Tessa: So you're getting a reputation for being a bit harder now?

Mick: No no, I say 'no no'.

It appears more tolerable for Mick to frame the threat to self in terms of being too generous, as he always has been, rather than forgetfulness and losing control. Mick rejects my suggestion that people are taking advantage of him, something he stated previously, perhaps because inhabiting a narrative of himself as vulnerable is intolerable. As Boyle (2003) argues, 'vulnerability', particularly in contexts of professional care, constructs a negative, socially conferred identity associated with helplessness and powerlessness. As Mick's narrative below demonstrates, his reluctance to construct himself as vulnerable appears justified

when this identity appears to have been legally assigned to him, with negative consequences.

3.1.2. Personal narratives in interaction with the socio-political

As hinted at above, Mick's hard-won sense of personal agency appears under current threat. Throughout our encounter he shifted between his apparently well-worn story of independence and having made his own way, to a frightening position of losing control. His struggle is particularly vivid in his narrative of his close friend gaining power of attorney over his finances. Mick's above denial [492] that people are taking advantage of him immediately followed the below account of his experience of a serious abuse of trust:

[480–490] I'm forgetful, they aim to use the law against me, well you gave it, he had the power to use it, you know, it never gets round to the fact that the man has a problem, he wasn't aware of this ... Yeah.

Tessa: So, do you think that people are <Mick: It's turned me> taking advantage?

Mick: Yes. Yeah. Now nobody's perfect, I'm not perfect [3]. But it's turned me. I couldn't believe it [2] he nearly lost, he has three houses he nearly lost them ... and I he was about to sell one as an ... and it all died down, without this we'd have been very friendly. ... and now and I ask for my money back he said 'no' ... And I wanted it to buy, buy things, and he wouldn't even give me the price of a loaf of bread ... I mean that's the insult, that's an insult to me.

Mick's personal narrative of an abuse of trust is told with clarity and determination in our interaction, despite my interjections around 'people taking advantage'. Mick affirms his personal identity by reinforcing his own capacity to resist others' attempts to push him around, whilst also recognising the strength of the legal discourses to alter his persona, and the attendant concrete limitations imposed on him (van Langenhove & Harré, 1999). Rather than speaking of himself as vulnerable, Mick has 'turned' instead to become hard, talking angrily, rather than fearfully. The narrative strength of Mick's sense of self provides evidence to

support previous research that self and the capacities to communicate a clear sense of such remain intact for PWLD (Sabat & Gladstone, 2010). There is, however, an implicit understanding in Mick's account that his forgetfulness is a problem, although he does not allude to any diagnosis which might more formally relate to his legal standing.

Nonetheless, Mick narrates an apparently concretely realised positioning act (via loss of financial control) which challenges all other attempts for Mick to re-position himself as autonomous. His story demonstrates the influence of the biomedical model within law, and macro social constructions contributing to passive identities, the 'demented' as legally 'non-persons' under 'expert' control. In a context of poor reliability and validity of dementia diagnosis (Fox et al., 2013; Harding & Palfrey, 1997) there are serious ethical concerns when medical diagnoses are linked with legal rights. Whilst a diagnosis of dementia does not necessarily indicate incapacity, assumptions of incapacity based on diagnosis are evident in research and practice (Helgesen et al., 2010; Hernandez et al., 2010). Although we do not know what has happened to Mick's finances, or how this relates to any capacity decisions, loss of self-determination is a serious threat to Mick's identity.

By attending to Mick's use of everyday language such as 'forgetful' we understand something of how he constructs his memory problems, perhaps as an age-related problem, rather than a diagnosable illness. Mick's constructions of his difficulties point to how he might wish to be treated; i.e., with respect and others simply understanding 'the fact that the man has a problem' [481]. This points to models of dementia care which enhance his personhood (e.g. Kitwood, 1997), with others fully acknowledging both his self-identified problems and his rights.

Mick attempts resistance, within the constraints of his current context, for example self-positioning as an authority over others:

[14] Well, you can't discipline [*the staff at the sheltered home*], cos they haven't got it mentally.

Perhaps Mick's self-positioning here is an attempt to preserve, or re-assert, his sense of self as an educated man, within an environment over which he is losing control.

Rather than enabling independence, as is the oft-identified purpose of dementia care (e.g., DoH, 2009a), implicit in Mick's story is that 'care', in this case sheltered housing, equates to a form of control. Although he attempts to resist subjugation in the context of his own finances and home, Mick has lost enough to be fearful of further loss, and so self-silences:

[35–37] Tessa: Yeah. So you think the staff here/

/Mick: No, no they're I don't know ah [3] I don't know, erm, [2] what to say.

I think you've to be careful what you say.

Despite Mick being noticeably affected by cognitive impairment, with word-finding and attentional difficulties, there was a sophistication to his talk about his position. He positioned himself as superior to others around him, whilst at the same time appearing very aware of the distribution of structural power, i.e., the more powerful health and social care staff. Mick conveyed a sense that he is *able* to speak, but that this is situationally inadvisable. Given all-too-common revelations about abuse and failings in care for older adults in the UK (e.g., Equality and Human Rights Commission, 2011; Francis, 2013; The Patients Association, 2011), this self-protection seems a reasonable precaution. The appropriateness of criticising care, seen in other participants' stories, may also be understood in the context of the values common to this particular cohort, who experienced life before the creation of the NHS and what is generally perceived to be the privilege of free health care in Britain (Fredman & Rapaport, 2010).

Narrative analysis is often concerned with linking the past, present and 'potential future', i.e., with asking what the particularities of a story can tell us not just about what is or has been, but about what *might have been* or *could be* (Andrews, 2014). Absent but implicit (White, 2003), within Mick's narrative below is the possibility of interdependence and trust. One is led to wonder whether the current

threats to Mick's personhood could be ameliorated if he was in some way alongside others:

[440–443] and we, we had no electricity and everything was candle lit ...
er we had to live by our means ... but there was no such thing as house
breaks or robbery or anything like that ... we were all on the one boat.

Threads throughout Mick's narrative, such as links with a religious community, point to potentially meaningful sources of such interdependence. Mick also described a genuine social quality to his relationship with his care-coordinator, who he has known for several years, which appears to enable him to be more open about his difficulties, and to accept support. This is evident in Mick's story of getting lost and helped by his care-coordinator on a recent trip to the local shops near his new home:

[278–282] Do you know how he found me here? He went into the
supermarket and the, er, the chemist shop and he said 'Does anybody
know Mick O'Driscoll?' You couldn't play it! I walked in, he said 'I've been
looking for you!' He said 'Oh Mick'.

Tessa: Oh, so he sort of goes out of his way to/

/Mick: he does yeah, that's right.

It seems that both humour, and every-day conceptualisations (e.g., forgetfulness, getting lost), enable Mick to maintain this supportive relationship with his care coordinator, without recourse to more formalised (e.g., medicalised) representations of his difficulties. Mick's narrative supports the literature on user views of dementia care which highlight the social role of services (e.g., Brataas et al., 2010). The longing for being 'on the one boat' indicates the social exclusion of older people with cognitive impairment. These findings support Dupuis et al's. (2012) call for care practices which comprise 'authentic partnerships' and enhance the 'humanness' of each through valuing interdependence.

3.2. Sid

Sid requested that his wife Rose remain present for our interview at their inner-London flat, explaining that she was comfortable in her armchair, and could ‘help me if I get stuck with remembering’. From the outset Sid demonstrated a keen awareness of the importance of others in maintaining selfhood. I explained the importance of user views, and both agreed that Sid would answer as much as he could³.

Analysis of Sid’s account identifies a key narrative which draws upon the biomedical model of AD, and his attempts to separate his personal and social identity from the diagnosis. His account hints that identity is at risk, and the incompleteness of a solely biomedical framework. Rose, and myself as interviewer, attempt to protect his preferred identity, at the cost perhaps of fully acknowledging threats to self and the associated stigma of memory loss. Sid persistently sought validation of his understanding of AD and his identity, indicated in the recurrent use of the phrase ‘you know/know what I mean?’ at the end of his narratives, with the effect of inviting co-construction of his identity and experiences.

3.2.1. ‘If there was a stronger tablet, I’d have thought they’d have given it to me’ [527].

Sid made clear from the first moment, and frequently repeated, his position that he has a medical condition, AD, with medical treatment the only relevant response:

[9–11] [*the GP*] was the one who diagnosed that I ‘ad the beginning of this Alzheimer’s and he said ‘I’m gonna prescribe you some um, some tablets, which you’ve gotta take regular, as prescribed’. Which I do.

[20–24] Tessa: So how, how do you find that relationship with your GP? Is it enough for you, for your needs at the moment?

³ Both Sid and Rose verbally agreed to be recorded and included in the analysis and written thesis.

Sid: Well, I thought that if there was an alternative way of helping, he would have told me ... You know, he would have either said 'you could go to blah blah blah' ... and they would give you this and give you that, which would slow the progress down, or make it better for you'

[65–68] Tessa: So in your mind, is there anything, a type of service that you could imagine that would be helpful at the moment?

Sid: Well, if I was advised by, you know the proper people that it could help, I would go there. But I'd have thought that the doctor would have said that all the same, you know what I mean?

[70–72] Cos *[the GP's]* quite good, and I'm sure that he wouldn't neglect you if he felt that there was something else other than the tablets that would help you, I'd have thought he would have recommended ... it.

[524–525] ... other than medicine I can't see what can help you out, you know what I mean? So the doctor's given me tablets

Sid's clear positioning of his experiences within the medical frame enables him to reinforce his trust in medical authority to know what is best, and to side-step my questions suggesting alternative frames, such as relational caring. This reluctance to 'break frame' (Harré et al., 2009) appears to serve several functions for Sid: offering the hope of cure, reinforcing his beliefs in a social contract in which authorities can be trusted to provide appropriate treatment, and, as I explore below, an attempt to separate and protect his self and social identity.

However, as Sid hints above, there is a possibility that his medical care is insufficient. In raising neglect as a possibility, I wondered whether politeness, cohort effects related to gratitude, his respect for authority and his own lack of authority within the medical frame, might affect his entitlement to speak against his medical care, alongside attempts to defend against vulnerability and fears of poor care. As Behuniak (2010) argues, the biomedical model of AD guides treatment which undermines the citizenship and rights of older people by emphasising their dependency as patients. In the context of Sid's life history his

deference to authority might also follow his military experience and participation in social clubs, such as the Rotary, which function within hierarchical organisational structures. Sid's use of 'you know what I mean?' suggests that he wants to hear my endorsement of his position. It is unclear who, other than medics, might be positioned by Sid as 'proper people' to advise him.

Despite his apparent faith in medical treatment, Sid's narrative also highlighted incongruences within a biomedical model of dementia:

[274–276] well I think as we all know, that as you get older you're gonna get, you know, as Rose said, the prostrate [sic], and I had er, me eyes troubled, we accept because as you get older they deteriorate, and so you're gonna have these problems, but they can be cured, as opposed to [2]

As Sid trailed off here, he highlights confusion as to what type of problem dementia is; it is linked to both old age, and medical conditions, but seemingly not fully explained by either. This could be a reflection of confused policy narratives, which combine the language of disease epidemic with ageing societies (e.g., DoH, 2012), and the inadequacies of the biomedical model at present to point to a cure (Fox et al., 2013).

Sid's general recourse to the medical frame, however, renders social responses to dementia incongruent. He discussed a monthly AS peer support group, which he enjoys, but is dubious about its function:

[57–64] yeah they're very helpful down there, and they're always coming around looking if you want cakes, or tea or whatever, you know what I mean ... and it's quite good, it's quite good.

Tessa: And in terms of the memory side of things, does it help with that in any way?

Sid: Not really. [2]

Tessa: No?

Sid: No. No. No, there's no talk about Alzheimer's at all, you know? Which could help you, or whatever. It's just a gathering, a meeting, and a little chat to each other.

Despite its enjoyable aspects, Sid's apparent rejection of the ameliorative value of social approaches may reflect the reductive nature of biomedical definitions which encourage a focus on dementia cure or prevention (Fox et al., 2013; Sabat & Gladstone, 2010).

Although unassociated with dementia care, the social domain remains rich for Sid:

[174–175] I do quite a bit of you know, meeting friends and that, I can rabbit, as the wife could say.

Nonetheless, Sid also hinted to the potential isolation of ageing with memory problems, and at times recognised the value of the support group:

[43–45] to meet other people and converse with each other. It's quite a pleasant event, you know what I mean? And it gives you a break to get away from here.

It appears then that Sid ascribes a personal value to social support, which fits with the type of person he has been throughout life, but rejects this in relation to professional care:

[169–170] I don't know that there's a way that *[the services]* can converse with me that can improve it really.

[650–651] well, I get involved in anything [2] cos I'm that sort of person. I'm not a person likes to sit around you know what I mean?

3.2.2. Preserving the self: 'All I can say is people who I talk to would never think that I've got Alzheimer's. I'm not trying to say I haven't got it' [126].

The above subtitle suggests the importance to Sid that the AD is not visible, perhaps implicitly conveying his awareness of the associated stigma. This is congruent with research findings that for people diagnosed with early-stage AD, negative experiences of stigma associated with the diagnosis exceeded any other self-reported problems (Katsuno, 2005).

Rose joined Sid to reassure him that the dementia is not visible, perhaps also to reassure herself that her husband's identity is preserved:

[189] Rose: That's what I mean, you can't tell *[at the carer and user support group]* who's got what.

Whilst Sid may wish to preserve his sense of self, he is nonetheless clear that attempts to reassure him fail to fully attend to what he is struggling with:

[216 – 17] it's just, it's the fact that it's frustration because [3] there's things that I should know and I've forgot, you know what I mean?

[225 – 231] Rose: yeah, well I find this day and age, whether young or old, everybody's forgetful

Tessa: The times I've got to Sainsbury's and I haven't got my shopping list with me (Sid laughs) It's no hope is it? <Rose: overlapping inaudible talk, 3 seconds>

Sid: So it comes that I've accepted it that there's no cure for it and erm, I just live life as usual, you know, we go out and about you know and carry on life as usual. And if I got worse, Rose would let me know, you know what I mean?

Despite living 'as usual', Sid makes clear that he is faced with a serious problem, demanding acknowledgement, which again he seeks with 'you know what I mean?' In our responses, I also wondered if Rose and myself were threatened by

the possibility that Sid, so sociable and in control of our encounter, is losing his memory, and attempt to deny, or minimise the problem. This dynamic relates to Foucauldian analyses in which the health of one threatens the social body, and can result in 'othering' to preserve our own health (e.g., Armstrong, 1983). Rose and I, rather than 'othering' Sid, resort to denial of difference, and perhaps of despair. Sid's assertions that if things worsened, his wife would let him know, point to his valuing of an interdependent relationship, which would require Rose to fully acknowledge his experience.

Sid is apparently aware of the limitations of medical treatment for AD, and concerned about the impact and requisite self-management of the symptoms worsening:

[133 – 137] I just accept I've got it, and I've gotta use a bit of common sense and don't do silly things, you know what I mean?

Tessa: What would silly things be?

Sid: Something that you don't generally do, which would create a bit of problem, you know what I mean?

Sid attempts again here to make sense of what kind of a problem AD is. On the one hand it just requires 'a bit of common sense', a statement which both minimises the problem and suggests that my questions about care are over-emphasising the support required. On the other hand, my experience of Sid as a proud and active man, and with this cohort in general, points to the significance of the word 'silly'. Doing something 'silly' would undermine Sid's identity, as he hints at stigmatising discourses around 'silly old people'. This excerpt reflects a shift in Sid's narrative out of the medical frame, to the domain of identity, both publicly produced and personally experienced. The concern around being seen as 'silly' points to his sharp awareness of normalising judgement, of social norms related to self-control and social deviancy. The burden of responsibility to self-control in this context also points to the individualisation and pathologisation of wider discourses, including the medical discourse (Harding & Palfrey, 1997).

3.3. Flo: 'I've no complaints about anything'

3.3.1. Telling without speaking: 'I just respect their position'

My initial experience of Flo was that she repeated herself, and at first I linked this to her memory problems. This suggests that, despite my intentions, I still brought to the encounter assumptions about the effects of cognitive impairment on people's ability to communicate their views. There were twelve occasions in our conversation in which Flo said either the exact phrase or a close variation of 'I just respect their position'⁴ when talking about professional carers. Although noticeably affected by memory problems – for example, forgetting within minutes that she had shown me her book of reminders – Flo's repetition of this stock phrase appears to have a rather more subtle effect in conveying that she has opinions about professionals, but there are reasons not to speak. Indeed, Flo both subtly and directly articulated how her position as an older woman with memory problems, in receipt of health and social care (including personal care support at home daily), affects her entitlement to speak:

[174-175] Tessa: Yep. And so whether that's a doctor, or a, someone at the library/

/Flo: I just respect them with their position they hold.

Tessa: Ok, yeah.

Flo: I think that's the way it should be isn't it?

[368 – 370] Tessa: So actually, it's the social stuff that's more important to you than the sort of, the healthcare side of things?

Flo: Well, I mustn't say that, cos they might stop the healthcare.

[378 – 388] Tessa: And if you ever wanted, if you ever thought actually there was something that wasn't as good as you wanted it to be, would you ever [2] speak up about it?

[3]

Flo: (whispering) No.

⁴ [Lines 180, 191, 199, 262, 264, 266, 376, 383, 402, 405, 430, 433]

Tessa: You wouldn't?

Flo: I just respect them.

Tessa: Ok. And what do you think would happen if you did speak up about it? Would you worry about [1] something happening?

Flo: I'd ring my family.

Tessa: You'd ring your family, yeah, and deal with it sort of privately, in that/

/Flo: Yeah and er [2] and they'd tell me if I was wrong in what I was thinking

Whilst on the surface conveying respect for authority, as Sid also did, Flo hints that she might think other than what she says, but is restricted in some way as to the answers she can give. Whilst Sid appeared to have a deeply held respect for medical authority, Flo hints that she might have criticism about her professional care, but is concerned for the consequences of criticism, most notably cuts to provision. Alongside this, Flo also questions the validity of her opinion. As with Sid and Mick, her self-censoring may at least partially reflect cohort values regarding gratitude for free health and social care. Indeed, Flo directly refers to this historical context:

[285] And one thing I do say [2] growing up we were very poor, there was no welfare state.

Given the current UK context of fiscal crisis and health and social welfare cuts (Lister, 2013), and Flo's recent experience of reduced social group provision, she is concerned about the concrete implications of appearing less than grateful for her care. Flo's opening response to my initial prompt about stories of care was to ensure she conveyed her gratitude:

[4] I'm very grateful for all the help I get.

Flo used the word grateful in relation to care eight times⁵ within the first five minutes of our interview, for example:

[64 – 65] *[the home carer]* will make sure my meal is warm, and I'm just grateful, that's all I can say.

[90-91] Tessa: And do you find it easy to accept the help?

Flo: Oh, I'm just grateful

However, an initial reading of Flo's narrative indicated an undercurrent of critique regarding her care provision, and subtle resistance to the reduced rights assigned to her as she hinted at preferred ways of caring. In response, my analysis of Flo's account is particularly concerned with the contextual factors, both within our encounter and more broadly, which influence Flo's positioning and entitlement to author her story.

3.3.2. Proximal and distal influences on the right to author

Flo's narrative appears to exemplify the position she holds in relation to others. It is difficult to know to what extent my association with professional care, introduced as I was via the AS, or Flo's perception that I am the more cognitively able communication partner in the context of her memory problems, lead her to doubt the validity of her opinions and seek my approval for her responses:

[34] But as I say, I'm very grateful for whatever I am [2] shown to do. Is that, er ... sensible?

[195] Sorry if I'm wrong.

Drawing upon narratives of PWLD 'lacking a voice', perhaps needing support to 'speak out' (e.g. Robson et al. 2008), I was guided by a desire to elicit what I understood must be Flo's 'real' opinion of services. However, I only seemed to intensify her wish to convey her respect for her carers:

⁵ Lines 4, 34, 62, 65, 82, 84, 91, and 93.

[260 – 264] Tessa: do you think (*the home carers*) respect you?

Flo: Oh, I'm sure they do. But they're here to do a job...They're not here to make me laugh, or [3] speak naughtily. They're here to do a job, and I respect that position.

Tessa: And as they do it, the way they relate to you, how does it feel?

Flo: Oh, I respect their position, that's the only answer I can give.

[401–406] Tessa: Yeah, yeah. And you had a social worker come this morning? Is that right?

Flo: uh, [2] let's put it, they're here to do a job and I respect their position. That's the only, you with me?

Tessa: yeah

Flo: I wouldn't say 'Oh hello Jane, or hello Lynn' I respect that from that I'm just gonna answer their questions.

In these excerpts Flo lets me know, and checks that I have understood, that she respects professionals and views herself as an obedient recipient of services, i.e., she is there to answer questions for them, as opposed to them being there to be friendly, or for her to have an opinion about what they are doing. This relates to my concerns regarding who dementia care is ostensibly for. I found it hard to grasp Flo's understanding of what her care was for, e.g. for physical health problems, memory problems or social isolation, and I wondered whether this again reflects a filtering down of the poor clarity in dementia policy (e.g., DoH, 2012) and guidance (e.g., NICE, 2013) regarding the aims and tasks of care. What is absent but implicit in Flo's view, though, is the type of caring relationship she might value, i.e. in which someone, with whom she is on first name terms, is there to make her laugh, rather than focus on care tasks. There are also hints in Flo's narrative to the social control engendered by health and social care provision (Harding & Palfrey, 2007), as she talks about her compliance with answering professionals' questions, and how 'if I make a mistake the ladies will rectify my mistake' [6].

Following Flo's story more naturally, rather than pushing my agenda about her opinion on dementia care, appeared to enable her entitlement to author her selfhood, and was more revealing as to her self-positioning, and what she might value:

[102–112] In my mind, I'm still 'Ginger Flo'! (both laugh)

Tessa: Are you?

Flo: Who knew it all...because I had a good education

Tessa: Did you?

Flo: Because, as I say, I was taught French

Tessa: Were you?

Flo: Yeah je parle Français. Vous parlez Français?

Tessa: Un peut (both laugh)

Flo: Yeah, so you see, I'm not kidding.

There was a shift in tone here as Flo 'pre-positioned' herself, i.e., justified herself as knowledgeable by providing factual evidence (Harré et al., 2009). This enabled Flo to have authority in our exchange, which is strengthened as I acknowledge her position. As Harré et al. (2009) outline, this pre-positioning and acknowledgement enable the speaker to have a 'footing' in the conversation. The move away from talk of dementia care, which prepositions Flo as an invalid (Sabat, 2003) enables her to subsequently share what type of support she does value:

[120–126] Tessa: So having the company around/

Flo: The company, I do like company! Yeah.

Tessa: And is that why you go out these places like [*names community group*]

Flo: Oh, absolutely, absolutely. And as I just mentioned, if I'm not going to a club, [*her daughter*] is on the phone, so we still have [2] contact.

Tessa: yeah, sure. Ok.

Flo: Ok?

Although Flo still checked with me at the end here that her opinion was acceptable, there was a noticeable shift in tone as she showed her enthusiasm for social support, which appears to have established an entitlement to author her story:

[136–137] Tessa: And what is [*the community centre*]. Can you tell me a bit more about that?

Flo: Oh, it's wonderful, it's um [2] how can I explain it? More like a social meeting.

[142–143] Tuesday I go to the library. Wednesday I don't have no contact, but I survive it by hook or by crook.

[149–154] Friday is [*the Church social*]. Which I go reluctantly ... For some reason or other, [2] you know how sometimes you meet one crowd of people and you can relate to them? ... And you can meet another crowd of people you think 'Oh, I don't like this very much'?

Flo again conveys the value of social support; indeed, the day where this is absent requires survival. She also expresses her preference for being with people she can 'relate to'; although when not available she will seek what social contact there is. As with Mick, and previous research findings (e.g. van Zadelhoff et al., 2011), Flo points to the value of personally meaningful interdependence, and everyday conceptualisations of social relationships, rather than broad professional agendas such as 'enabling independence' (DoH, 2009a).

Flo's entitlement to 'self-narrate', in regards to her personal and social life particularly, was not sustained, as she silenced her views about her formal care provision for most of our encounter. This suggests that Flo's experiential knowledge of professional care may not be perceived as sufficient to entitle her to speak on it, constructing her instead as a passive recipient. This demonstrates the tenacity with which broader discourses about dementia care, which pre-position people as deficient objects, denies individual rights, most notably the right to speak (Cotrell & Schulz, 1993; Dupuis et al. 2012).

3.4. Group analyses

The group comprised three men and two women, one of whom, Mrs Kalil, was only able to attend the first of three weekly sessions. As the collective narrative unfolded, I learned that the group has known each other for several years, through various permutations of dementia service provision.

To structure the analysis, I present each group as a subset of data. However, the key narratives and context for telling are shared and developed throughout; the distinction is primarily for ease of reading, and transparency regarding the processes of data gathering. The analysis is structured around the ‘big stories’ of each (both individual and collective), i.e., key narratives which tell us something about people’s experiences, pre-occupations, personal philosophies, etc., in relation to ‘small stories’ (Baldwin, 2006; Phoenix, 2008); i.e., which privilege the fleeting, or fragmented, telling of ongoing events, the hypothetical, or allusions to stories untold. These are analysed with consideration for how they contribute to the performance of identity in everyday interactions within the research, service and wider socio-political context, and what this might tell us about what is valued in regards to care.

3.4.1. Group 1

[115–116] Thomas: and they do their work well and [2] and er [2] they er, there’s a [2] and if they like this place they should give it good reputation

Thomas responded to my opening question about his experiences of care with a seemingly ‘objective’ evaluation of the IDS. He followed this by assuming authority in the conversation, taking an almost teacherly tone to control our encounter as he advised me regarding standards across ‘most things’ in life:

[117 – 122] Everything’s good.

Tessa: Do you have any examples of things that are/

/Thomas: It doesn’t matter what you’re [5] There’s a certain limit in life ...

Now [2] I think some, most people will agree with me [5] Most things are

pretty good <Tessa: yes> ,and these things can't be altered, they'll always be good.

Thomas then sought acknowledgement from his peers for his contention, supporting Riessman's (2008) suggestion that the purpose of narratives in groups can be both to persuade and argue and to foster group belonging, both of which Thomas does effectively:

[122 – 127] Would anybody disagree? [1] eh?

Lionel: No

Mrs Kalil: uh uh

Thomas: You don't disagree?

Lionel: Yes, I agree with you

Pam: agree, he agrees with you.

This contrasts with Flo's questioning the validity of her responses in the interview setting, as Thomas pre-positioned himself in the group, and is acknowledged by peers, as a knowledgeable elder man, rather than a user of dementia care. To support this is Thomas' key narrative, subsequently told, of his worldliness via a career in the merchant navy, with the effect of pre-positioning himself as credible to offer an opinion about 'standards':

[128 – 142] well, to be quite honest I've been all over this world my dear.

Tessa: you've? I'm sorry?

Thomas: I've been all over this world, in different trains, every, everything

Tessa: I can't catch what you're saying

Thomas: and I've [3] and most things I've found are very good.

Tessa: oh ok. And what makes them good?

Thomas: [2] erm the people themselves. The people who are doing the work makes things good ... cos they do their work well and er they're quite happy

Tessa: umhm

[4]

Thomas: You can't disagree with that.

[152 – 158] And er I've had a pretty good life[1] The er, lots of ships at sea, shipping all, most of my life and I've had good ships, most of them are good ... I'll let you understand. Nowadays you have a standard ... You realise what I mean?

Tessa: Yes

Thomas: We have a standard ... at every company, and shipping companies must pay attention to ... You understand sir?

Lionel: Yes

Thomas is firmly in control of his narrative. By addressing me as 'dear', ignoring my attempts to follow what he is saying and recruiting our agreement, he successfully prepositions himself to impart his knowledge of 'quality' by extensive experience. We cannot know Thomas' intention, or whether he consciously had one, in telling his story; narrative analysis requires interpretation and recognition of the allusive nature of stories (Phoenix, 2008). Thomas may have been motivated to use identity as a resource (Antaki & Widdicombe, 1998) to preposition the validity of his opinions, or perhaps simply reverts to the comfort of a well-worn personal script to mask cognitive difficulties with following the conversation. As with Mick's narrative, he may subtly take his story away from the negative identity of 'vulnerability' associated with being a recipient of professional care (Boyle, 2003), with narratives about the past more congruent with his sense of self. Whatever the intention, the effect of Thomas's pre-positioning gives him a footing in our conversation, acknowledged by others, to express his views (Harré et al., 2009). As I sought to clarify the connection between his past and the topic of care, there does appear to be some link made between the responsibilities of a navy crew to provide 'proper food and proper conditions' and those of the staff at the IDS:

[205 – 207] ... shipping is different these days, everything's up to standard ... They've got a high, fairly high standard ... of living which means we get good food and everything

In talking in present tense about standards, Thomas suggests that his current provision is good, with improved standards compared to the past. Such can be contextualised within Thomas' cohort, having witnessed huge expansion in free health and social care provision in his lifetime.

In contrast to Thomas invoking personal authority by experience to evaluate standards, the women in the group drew upon key narratives of family life to develop their stories, and our understanding, of what is valued in care. They began with sharing what they value with the IDS staff:

[8–12] Mrs Kalil: Well, it's beautiful, innit? <Pam: uh huh> The staff is lovely.

Pam: They're wonderful, all of them/

/Mrs Kalil: Yeah, lovely, yeah. And they're very nice and very umm/

/Pam: Caring.

Mrs Kalil: Caring and er love, they love with us. Yeah. They hug us, kiss sometimes you know.

[34–36] Mrs Kalil: Yeah, they come and ask us 'hello, how are you?' this and that, and we miss you. We say the same in reply ... So sometimes we are emotional, hug each other, and er, and that's it, kiss, kiss! (laughs)

Mrs Kalil claims her entitlement to narrate by drawing Pam into agreement with her and using quotes from staff to develop a vivid account. Although using different devices to Thomas, you again cannot disagree with her story. These habitual 'small stories' of care suggest a genuine emotional bond between the service users and staff. However, Mrs Kalil is also clear that professional care cannot replace that from family:

[305–311] No, family's always different, innit? ... so I've got no complaint about this staff or in this er centre, there are myself I can see all is good <Pam: Hmmm> nice, lovely, caring. And if I'm sad they're asking 'why you're sad, tell us, tell us'. Sometimes you need somebody to ask

something you know <Pam: Speak to you> yeah. They have to, I don't think so, I don't have any complaint about them.

Mrs Kalil talks of a genuine care that she does not think staff are obliged to offer; yet they do. In stating 'all is good' at the service there is a hint that the more complex topic warranting discussion may be family relations. This fits with her key narrative of the pain of mistreatment by her husband's family, when she moved to them in Africa from Pakistan, before moving to the UK:

[264–269] I'm very um special baby ... for my mother father and sister brother. Since I married, after that is my period of bad start (Mrs Kalil and Pam laugh loudly) ... Since now, about 50, 51, 52 years ago, since now, er I'm suffering.

[282–286] Tessa: And did anyone look after you in that time?

Mrs Kalil: In there, in Africa, nobody, nobody ... yeah because all new relative and new people because er I married in not my family ... out of family, so we no-anything, just er blood you know. So er and and nobody er there for, for er help me or something you know. And er it's passed, if I remember then I go again (shows hand moving face down, shoulders slumped forward).

There is an exception to my transcription conventions here with a representation of Mrs Kalil's non-verbal communication, as she clearly used the gesture in place of a verbal description of the effect of painful memories. This may speak to there being no words for her pain, and/or a loss of language acquired in later life, which is associated with ageing and dementia (Hyltenstam & Obler, 1989). Mrs Kalil's key narrative of the failure of people who are not her biological family to care for her appears to link to her ongoing desire for genuine caring relationships, which is valued by her both within and outwith her family, although particularly missed within:

[313–314] Because now I'm alone ... They all gone away, own homes, and own er families and this and that

[324] so that's, that's the sad story for me

Mrs Kalil's story reflects previous research that indicated a cultural trend towards young Asian adults in the UK leaving the parental home after marriage and changing assumptions about inter-generational reciprocity, which can be a source of shame within cultural beliefs that stigmatise professional care (Seabrook & Milne, 2004). In contrast, a genuine partnership model for care (e.g. Dupuis et al. 2012) might enable culturally appropriate connectedness between PWLD, informal and professional carers to work together, reducing the care burden on family whilst engendering reciprocity.

The group context enabled Mrs Kalil's stories of family to prompt Pam's:

[330–333] I've got an eldest son, I got an [inaudible, 1 word] he texts, texts my daughter regular and always says to her 'how's mum?' and I said, and I reply, I said 'ask him to pick the phone up and ask, and phone me! I'm 'ere, I'm always 'ere apart from the hours I go to [*the local shops*]. Pick the phone up and ask me yourself'. I'd like to speak to him.

As Mrs Kalil did, Pam also uses quotes to enhance the credibility of her story. In doing so she conveys her desire for more frequent contact with her son, whilst firmly placing the responsibility for the lack of this with him. Pam draws upon her family story to demonstrate her wish for connectedness whilst remaining autonomous:

[336–338] Ah, ah [1] well I've always been very close to my family, you know? I've never depended on them for anything. There are times I've needed a lot [1] I've never had to go to hospital or anything but apart from that no, I've made it on me own, coped on me own, I like me own independence

It is interesting that Pam mentions in the one sentence that she is very close to her family, but does not depend on them. This relates to systemic perspectives

on the family life-cycle (e.g. Carter & McGoldrick, 2004) which theorise individual development towards an interconnected yet autonomous self, with the balance between independence and dependence being in part culturally situated, and re-aligning with age and increasing care needs. Both Pam's and Mrs Kalil's stories share the disappointment at lack of contact with their children, although the meaning of this may differ according to the cultural contexts of each. The two women again prompted each other to tell culturally situated stories of neighbourly care, indicating valued identities. For example, Pam subtly initiated a move away from my questions around her receipt of care, moving the plot towards her independence. This supports Sabat's (2003) contention that PWLD may resist the 'malignant' positioning assigned by others. Following her lead elicited a narrative account which demonstrated her role in caring for others:

[355–365] Oh yes many neighbours I've looked after

Tessa: Neighbours?

Mrs Kalil: Like me <Pam: yeah, umhm> my neighbour is the same like Pam's neighbours

Tessa: So let's, let's can you tell me any example of when you looked after a neighbour?

Pam: Well one person who's still on the end she got flooded one day <Tessa: Oh no> and run along to me as quick as she could ... 'What's the matter?' and she said 'Can you come and help me please I'm flooded out and I don't know where the water's coming from'. She had a burst, in the winter she had a burst tank <Mrs Kalil: mm> come right through her ceiling her kitchen and everything was flooded ... and her children are far out so it's no good contacting 'em cos they couldn't come easily yeah so we had to get the plumbers in to see to her

The telling of this event highlights, firstly, that following Pam's lead provided opportunity for narrative expression on her own terms. This supports Baldwin's (2006) contention that PWLD can be narratively re-possessed when provided with opportunities. Although he also argues that we may need to redefine narrative, and move away from structural and temporal features, Pam used a clear and coherent narrative structure, rendered vividly with dialogue. We also

learn from this story that Pam views herself as, and provides evidence for, having a role in competently helping others. This story supports her claims to the rights and duties associated with her construction of 'independence'.

Pam's story prompts Mrs Kalil to tell a related, but distinct, story of her receipt of neighbourly care:

[373–387] my neighbour is er when they come to next me they are young and er now they are er come maturer or you know er er [1] old er middle aged and they give me respect like a mother, you know what mean? ... when er the scene er in my house is silent, no er type of noise and no hoovering or in ... then they bang the wall ... they bang the wall, <Tessa: oh no> yeah because er they they I er bang in return the wall ... because they know I'm I'm still alive <Tessa: ooh I see, ok> <Pam: right> yeah, yeah <Tessa: So they check, so they bang the wall to check> yeah <Tessa: and you bang back> (laughs) yeah ... so, so that's the, if I can't bang the wall then they come to back side door or come to door window knock the door or knock the window, if I can't reply then they call that ambulance or police then er if I faint along the floor or somewhere they are come and pick me, because the times for my er neighbours

Tessa: So that must be reassuring?

Mrs Kalil: Yeah they are like this because I look, I look after them also like mother, you know?

Tessa: Yes, ok

Mrs Kalil: So they give me respect, I give, I give love back you know? And so.

Mrs Kalil's story is one of interdependence and reciprocal caring, congruent with South Asian cultural and religious narratives which value respect and interdependence through communities and the extended family (Kaur Nijjar, 2012). For Mrs Kalil care and respect are not mutually exclusive, as it appears they might be for Pam as she manoeuvred away from stories of herself in need of care. Nonetheless, both women developed a narrative of relational caring within professional and informal networks. Their stories are congruent with Pearlin et

al.'s (1990) definition of caregiving as a relational process comprised of an affective component and behavioral expression of this. As per Brataas et al.'s (2010) suggestion, these findings contribute to cross-cultural evidence, in the context of individual life experiences, for dementia care experiences and preferences.

Both George and Lionel contributed less substantially to the first group, although were to an extent responsive to attempts to follow contributions from each at their own pace:

[45–55] Pam: Various things, whether it's current affairs and the quiz ... art and craft, everything

Tessa: Yeah, ok, so keeping you up to date/

/Lionel: Boy does she love a quiz! (shouting, all laugh)

Tessa: You enjoy the quizzes?

Pam: I do, yeah

(more laughter)

Tessa: So, is it for you Lionel, what else goes with the understanding, what else?

Lionel: Well uh knowledge

Tessa: umhm

Lionel: Uh, erm, uh, several other things you know they're all very very kind which is predominant ... in my mind.

[399–406] Tessa: And how, George and anyone else <George: yeah> how can you tell if someone really cares for you?

George: sorry?

Tessa: How can you tell if someone genuinely is caring?

George: [very softly spoken, inaudible first 5 seconds] I ended up at [*name of*] hospital [becomes inaudible again for 7 seconds]

Tessa: So when you went to hospital, the staff weren't helpful?

George: No, they were very helpful

As shown throughout the analysis, George refers to a lack of, and develops, confidence to speak as the group progressed. However, Lionel appears to have a more particular reason for not speaking:

[186–191] Tessa: yeah. So what are other ways that you saw kindness, in your life before here?

Lionel: well don't know. I live alone you see... and maybe that's why I'm talking [2] so please leave this from

Tessa: so, sorry?

Lionel: Please leave this from [2] I'm embarrassed.

Lionel conveys here that he becomes embarrassed and questions perhaps his ability and right to speak, as he is socially isolated. He returned to discuss his isolation again:

[525–531] yeah cos when I move out here, er I'm a single man

Tessa: yes, yeah, bachelor

Lionel: yeah in ingrained way

Pam: But you've got a good nephew, nieces and nephews

Lionel: Yes, he phones me up

Pam: Yeah he does, comes down and does odd jobs for you

Mrs Kalil: that's good, that's good

In raising the theme of loneliness, Lionel appears to preposition himself as unentitled to give his opinion. This speaks to the effects of the broader exclusion and invisibility of older people, and particularly those with memory problems (Dupuis et al, 2012; Sterin, 2002), in regards to communication ability, personhood and assigned rights. The above extract, when the women let Lionel know that he is not alone, indicates the value of joining with peers with dementia, congruent with previous research (Asquith, 2013; Dupuis et al, 2012). Lionel's account of single life when he moves 'out here' also implies that within the care setting he becomes something other. This speaks to the valued social function of dementia care, again congruent with previous research (e.g. Brataas et al, 2010),

and he proudly demonstrates his group belonging with his shout of 'Boy, does she love a quiz!'

3.4.2. Group 2

The second group analysis particularly demonstrates processes and effects of co-construction within a peer group. A key theme in both the content and telling of stories was the relational processes of bestowing rights and personhood. This occurred through collective acknowledgement and contribution to public personae, and seemingly also the individual sense of self, related to stories of past, present and imagined care.

3.4.2.1. Relationally bestowed rights and identity

Both Lionel and George contributed substantially in this second meeting, with Pam and Thomas remaining active contributors. Beginning with George, there is evidence that his footing in the conversation was enabled by others acknowledging and supporting his contributions. The participants and myself provided a context which supported George's pacing and 'scaffolded' his utterances to enable him to develop them. George's story of a previous group experience demonstrates the role of others in relationally bestowing his right, and enabling his ability, to speak:

[89–91] Tessa ... so you were saying that even though you only went the once or twice [*to a service user forum*] it was still an important thing for you?

George: Yeah it was, yeah, it helped me to get into some rhythm in the questions, being questioned, and they take a lot of notice of that.

His narrative supports Kitwood's (1997) contention that the 'social psychology' of how PWLD are treated, such as 'outpacing' in conversation, contributes to people's (dis)abilities. George's contributions developed throughout the encounter, as he made increasingly independent responses. As Killick and Allan (2001) argue, George has a clear sense of purpose in his communication, which requires only attentive facilitation.

[208–211] Tessa: ...Does anyone have carers that come to their home?

George: Yes I do

Tessa: You have a carer that comes to your home?

George: Yeah.

[219–228] Well she motivated me actually ... And I've got to know her so well after a few months it's been very very close yeah

Tessa: so it's over time, building that relationship?

George: That's right yeah. It's been very close up to now

Tessa: Yeah, yeah

George: You know. When I fell down the stairs at home [2]

Pam: Yeah, you had a good fall then, top to bottom, I remember that

George: Yeah and just the staff were fantastic really. Picked me up and took me in the ambulance

George also increased his interaction with the group, and contributed to a collective narrative regarding the social value of care, particularly reciprocity:

[277–281] Pam: They do something for you, and it's nice to give a return

Tessa: Yeah

George: That's right, yeah

Tessa: And it's not so appreciated if it's all one way?

Pam: That's right, yep

For Pam the shared humanity of service users and care staff was something of importance, perhaps in that it may support her own 'humanness' and, therefore, a less threatened identity and trusting (reciprocal) relationships in this care context:

[735] [*The staff are*] no different to what we are, human beings the same as us

Pam's position was made clear in contrast to another story of experience told by Thomas to justify his mistrust in others:

[708–713] Anywhere, and you go, you've gotta be very careful. Look, I'm talking...I worked in Dundee a long time and er I come from the country now most people [2] I used to work on buses, a conductor and that, you know?

Tessa: Yep

Thomas: and er you get to know people I reckon, on the level that you can talk to, but you still got to be on your guard all the time, it doesn't matter what you do.

Although their stories suggest different personal philosophies (Pam advocating shared humanity, and Thomas mistrust of others) both serve to reject being positioned as powerless or dependent upon others. As with Mick, however, there are hints that self-protection and mistrust may not be preferred by Thomas, as he narrates his relationship with peers at the IDS:

[533–537] It means a break

Tessa: A break

Thomas: I come and talk to my friends and things

Tessa: So it's the talking to other people/

/ Thomas: Yes, it's a good break. I like it anyway

The group context enables Pam to use identity as a resource (Antaki & Widdicombe, 1998), i.e. in constructing herself throughout as capable and independent she is pre-positioned to support others, particularly Lionel, in developing his contributions and his own social identity:

[310–319] Lionel: [*His cleaner's*] a nice girl

Pam: It must be nice to have someone to talk to really

Tessa: Yeah, definitely, yeah

Lionel: Well, it's part and parcel of it ...

Pam: Mind you, you've got a good neighbour, haven't you Lionel? That Polish neighbour, <Lionel: Yeah> he's very good

Lionel: Yeah [*names him*]

Pam: Yeah, that's right

Lionel: He's a lovely person and uh and I rely on him so much so

[367–375] Lionel: I'm outgoing for a start. I don't know whether Pam would decry this or not?

Tessa: (laughs) he's saying he's outgoing

Pam: Yeah, yeah he is

Tessa: So that helps

Pam: I've known him for a long while, interrupting, because when I first started the day centre in [*nearby area*] years ago ... he used to come over. I met him and I just used to muck about with him

Lionel acknowledges Pam's credibility (e.g., on what type of person he is), growing in confidence as she helps him to thicken his identity beyond his seemingly well-worn story, told in group one, of being a 'single man'; to a broader construction of himself as social, indeed outgoing.

Similar to Thomas seeking acknowledgement from his peers in Group 1, Lionel and Pam's telling indicates the value of peer support. Congruent with the theoretical assumptions of narrative approaches to therapy (e.g. White and Epston, 1990), the co-construction of experience between group members appears to enhance the humanity of each and expand possibilities for identities and, therefore, action. This supports Dupuis et al.'s (2012) call for local partnerships with PWLD, who may view each other as more credible from an experiential position, and on a more equal footing than with professionals. When Lionel demonstrably values Pam's opinion, Pam's own identity as a support for others is likely enhanced too. It is also possible that Pam requires Lionel to be more positive to protect herself from becoming contaminated by his isolated and dependent identity, which points to a context of co-construction, alongside the tenacity of identity threats related to being 'old' and 'demented' (Harding & Palfrey, 1997). Peer-support does not necessarily preclude a role for professional support:

[412–419]. Tessa: But it was a special thing for you to be invited it sounds like, if you've kept the letter [*inviting him to attend the IDS*]?

Lionel: Yes, yes, very much so, I needed it.

Tessa: What's it done for you then, what needs has it met for you do you think?

Lionel: Well it supplied me with a cleaner, five weeks, years, ago (laughs)

Tessa: So practical help?

Lionel: Yeah

Tessa: And what else does it do for you?

Lionel: Well, I'm not a bundle of joy, if that's what you mean, uh, no way so

Although Lionel did not finish his sentence here, he points to the value of the IDS for his mood, alongside supporting previous research regarding the value of practical support from dementia services, for example when the social care team organised home cleaning (Brataas et al, 2010). Following Pam's contribution to the construction of his social identity, Lionel seemed able to share his need for support, without apologising for his contribution as he did in the first group.

3.4.3. Group 3

Pam surprised me by beginning the session with a previously unvoiced view regarding what was good about the IDS:

[18–26] Well, for starters the memory, the brain ... makes you concentrate ... Where at times you forget ... It makes you really concentrate.

Pam directly links the social setting to improved cognition, supporting Kitwood's (1997) contention that impairment associated with dementia is to some extent related to 'malignant social psychology'. Pam's late introduction of this new topic also highlights the importance of collecting data over multiple occasions, to enable thicker narratives and interpretation within a broad context of 'big' and 'small' stories. Whilst some utterances may appear uncertain in meaning, the aim of analysis is to present an interpretation of a meaningful whole (Baldwin, 2006).

Pam soon returned to the theme of reciprocal caring with peers, and the emotional value of this:

[38–44] Tessa: So it keeps, it keeps <Pam: the mind> the memory <Pam: alert> and concentration ok. And what else makes it a good experience for you?

Pam: Well, it's the change of people. Most about the same age as you, might be a bit older, bit younger ... And you listen to their aches and pains and tell them your aches and pains, not that it gets you anywhere, but gives vent to the feelings

This develops her construction of her care experiences to incorporate both a cognitive and emotional value to social care, supporting previous research findings as to the range of positive outcomes associated with dementia care (e.g. Snyder et al. 2007).

3.4.3.1. Consistency of key narratives and relationship to stories of care

Pam and Thomas were able to perform key narratives which constructed and projected stable and preferred identities, such as independent and experienced, whereas for Lionel this was more dependent on the contributions of others. Lionel again told a story of his habitual loneliness, yet, whilst expressing great anguish over this, rather than denying his right to speak, he did so very powerfully:

[252–255] Lionel: Well I lead a bit of a lonely life ... I um, (inaudible word) which er, so maybe I'm speaking out of turn

[258–260] Pam: And there's nothing worse than being lonely Lionel/
Lionel: Yes <Pam: And I agree> and I'm very, sometimes I could scream
Pam: I bet you could yeah

The above extract suggests that the co-construction to develop Lionel's preferred identity (e.g. as 'outgoing'), struggles to take hold over time against the well-worn account of his loneliness, supporting evidence of the effects of isolation of older

people with memory problems (Dupuis et al, 2012; Sterin, 2002). However, on this occasion, as Pam more fully acknowledges Lionel's pain at being so alone, Lionel and Pam join in a shared experience of valuing each other and, thus, looking forward to coming to the IDS:

[272–275] Lionel: I look forward to coming here. Seriously...

Pam: And I look forward to coming here and I'm not on my own Lionel

Lionel: Oh yes

Again, the findings support social and peer support, and the value of opportunities for co-construction. I wondered whether this fuller acknowledgement of less desirable identities, such as 'lonely', was enabled by our group developing over time.

Pam articulated her desire to have others around, and contextualised this within her life history:

[381–385] Well I've worked with lots of people, in my time with jobs I've done

Tessa: Have you?

Pam: I worked at [*names film studio*]. I was a waitress on a licensed bar there.

Tessa: Oh right

Pam: So I had to talk to lots, lots of people

[392–394] Pam: As long as there was plenty of people there [*at any support service*] ... I'd be in my glory

The findings demonstrate the value of opportunities for collective narrative expression to support identities which may be under threat for PWLD (Baldwin, 2006). George directly articulated the value of our group talks for supporting his confidence and communicative abilities (again demonstrating the validity of Kitwood's (1997) social model of personhood), which he suggests is not always the case outside of the group:

[100–104] well, since last time we had a talk, I found it very interesting then

Tessa: Yeah, good?

George: It helped me a lot actually

Tessa: Having the conversations?

George: It's given me more confidence myself

[121–122]. Well, it means a lot, you know like I'm very hesitant at times, I have been ... so it's picking up something, that's what it's like, for a change

Thomas, also recognised the value of the group:

[169] And er, our little get together, it's very interesting at times

Although this recognition appears difficult for Thomas to reconcile with his attempts to occupy a position of authority, and is followed by a, at least partial, denial of his need for social care:

[183–184] You see otherwise, I'd be sitting at home er, I've got the daily paper to read, got enough that I can read, things like that, in a way, in a way I wouldn't be er at loss for something to do

Thomas perhaps tells this habitual story of his ability to occupy himself to reject the passive identities associated with dementia care (Behuniak, 2010; Sabat, 2003), and preserve his sense of an independent self beyond the care context.

3.4.3.2. Imagined possibilities

Whilst any narrative analysis requires an interpretation of the allusive nature of stories (Phoenix, 2008), in a dementia context there is particular value for the co-construction and interpretation of narratives between people with and without dementia (Baldwin, 2006). This was highlighted when I directly asked in Group 3

the hypothetical question 'if you were working somewhere like this and you wanted to make it a good experience for other people, what kind of things would you do? If you can imagine such a scenario' [476 – 477]. Participants struggled to respond to this, offering rather concrete examples related to past experience, such as George's concern that if he worked in care he would need 'to learn much more about illnesses and things like that' [515] as he 'used to be a lorry driver [518], and Lionel's suggestion that he would 'bump into people' [471] as he did when pushing trolleys in a past voluntary role as a hospital porter.

Cognitive flexibility, i.e. cognitive ability to generate alternatives, generally declines with age due to a combination of physical decline and opportunities for practice (Zec, 1995), with additional decline associated with diagnoses of dementia (e.g., Eslinger, Moore, Troiani, Antani, Cross, Kwok, and Grossman, 2007). These potential cognitive constraints suggest that the interpretative and co-constructive role of others can usefully aid the development of meaningful narratives of imagined possibilities with fragmented accounts.

Potential futures were implicit throughout the data and interpreted in analysis – for example, the possible implications of Mick's talk of valued past interdependence, or Lionel's broadening of his sense of a social self when others contributed to this story. Such interpretation expands the possibilities for co-creation of dementia care to develop creative, interpretive approaches to working with PWLD.

3.5. Summary of Findings

In the context of an unstructured approach to eliciting narrative accounts through interviews and group discussions, the results are striking in both the commonalities and distinctions across and between participants. By this I refer to the diversity of life histories, personal philosophies and identities narrated by individuals in the research encounter, which appear to interact with a much smaller repertoire of public narratives and associated positions in regards to ageing, care and memory problems. The sophistication and tenacity with which the participants attempted to resist undesirable positions (e.g., Pam's move

towards stories of independence, away from her care) and (co)constructed their identities (e.g., Lionel's social persona co-constructed in the group), and imagined possibilities for care (e.g., meaningful interdependence), attests to the communicative and narrative abilities of older PWLD, particularly when supported and facilitated.

This section summarises the findings in relation to the literature and research questions regarding the stories of care told and how the telling relates to local and societal contexts, before moving on to critically evaluate and consider the implications of the research. As signposted via headings below, the summary of findings relates first to my initial research question regarding what stories of care were told, and moves on to focus upon the second research question regarding how they were told. Both of these aspects of individual accounts have been linked throughout the analysis and discussion and are related throughout the below summary to the final research question regarding the implications for dementia care. The intentionally wide scope of the research questions and adoption of a narrative approach to data collection and analysis have produced findings with a primary focus upon the accounts of participants, with the research questions acting as a broad structural framework.

3.5.1. What stories of professional care do PWLD tell? Personal and public narratives in context

Eight older people, in receipt of UK voluntary and/or statutory care for dementia in the early twenty-first century, shared their stories with me. The cohort's stories are contextualised by enduring cultural views that universal free healthcare constitutes a privilege rather than a right (Fredman & Rapaport, 2010), a current health and social care context characterised by threats to provision (Lister, 2013), and policy rhetoric based upon under-theorised, confused public narratives of a frightening dementia epidemic and the financial burden of care for an ageing population (e.g., DoH, 2012).

3.5.1.1. The Constructive effect of care context

Both the collective group and individual narratives demonstrate the constructive effects of incoherent theoretical model(s) and aims underpinning dementia care. Participants drew upon biomedical, age-related, everyday and social frames to make sense of their care provision, but did not remain within any one particular frame. As Baldwin (2008) argues, and the findings support, there are ‘real-world’ consequences when policy and the resultant service provision creates the space in which individual identities are constructed. The group participants narrating within the social care context were more concerned with their everyday social identities (storying meaningful relationships and the effects of loneliness), than Sid, for example, whose primary care context was his GP, and whose narratives were more concerned with the possibilities for treatment, a passive identity and the stigma associated with a diagnosis of AD. As in previous narrative research in this field (e.g., Castro & Clark-McGhee, in press), it appears that whilst influenced by socially available and formally represented dementia care narratives in the UK, the collective narratives produced and analysed in the current research illuminated, interrogated and imagined dementia care beyond these often narrow frames.

3.5.1.2. How do PWLD make sense of care experiences? Theoretical insights via personal stories

Personal stories form the heart of the narrative analysis, both ‘big’ life stories, such as survival, authority, experience and loneliness, and everyday, habitual stories which demonstrate care and love, but also mistrust and fear.

In regards to under-theorised experiences of dementia care, as identified in the literature review, Reder and Fredman’s (1996) ‘relationship to help’ is a useful conceptual framework to summarise and expand understanding of much of the analysis in the current research. The framework links previous experiences and meaning-making with ongoing (co)construction and responses to dementia care. The relationship to care is unique to each, and narrative analysis enabled attention to explicit and implicit associations across past, present and future. For

example, Sid's relationship to help is narrated within apparently lifelong trust in authority, contributing to his reliance on medical care for AD and requests for validation in the research encounter. The medical model of care emphasises dependency as patients (Behuniak, 2010), which could lead to a feedback loop of ever-decreasing power and agency for Sid. This co-construction links personal experience and cultural narratives; despite Sid's best efforts to maintain his construction of AD within the medical frame, congruent with his personal experience, his implicit identity concerns highlight the effects of medical discourses in relation to societal stigma and threats to identity (Katsuno, 2005; Sabat, 2003).

These findings also demonstrate how biomedical discourses are consequential for individuals, and lend support to concerns that in the absence of a strategic approach to research and care to determine where it will provide tangible benefits, simply increasing screening and formal diagnosis of dementia may not be justified (Fox et al., 2013).

3.5.1.3. How do PWLD position themselves through the narratives told? The personal is political

The analyses also demonstrated that in a dementia context the personal is the political (Baldwin, 2008). For example, within a conversational one-to-one research encounter, Flo's agency and right to talk openly and author her own story was influenced by my positioning of her, which moved from unintentionally 'malignant' (Sabat, 2003), i.e. as a passive recipient of care, to my acknowledgement of her preferred identity and providing a footing to author her own story. This supports Bartlett and O'Connor's (2007) contention that existing models of dementia, primarily biomedical and person-centred, inadequately attend to the politics of being labelled with dementia and receiving services. These findings support the value of citizenship models of dementia (Bartlett & O'Connor, 2007), and as Adams (1998) argues, and the analysis here demonstrates, attention to language to enable theoretical and practical advances towards political models of care.

In response to the findings, in large part not ostensibly 'about' dementia care (e.g. about neighbours or family, instead), the very notion of 'professional dementia care' demands re-consideration. Perspectives of disability activists rejecting the term 'care' as oppressive and engendering passivity and dependency (Oldman, 2002), support a reading of the findings as a collective narrative of resistance for this passive positioning, and a re-positioning of themselves as active participants and agents in a relational context of support.

The particularities of the stories point to how this relational support might take shape. For example, as Mrs Kalil's narrative suggests, there is value in genuine, culturally-appropriate partnership between people with memory problems, family, informal networks and professionals. In privileging experiential knowledge, as advocated in progressive forms of research (Beresford & Evans, 1999) and demonstrated in the analysis, policy buzz words like 'independence' (DoH, 2009a) can become meaningful and operationalised, for example where Pam's personal narrative of 'independence' points to ongoing opportunities to care for others to support her sense of self.

3.5.1.4. Narrative re-possession

Also related to the question of how PWLD makes sense of their care experiences, the groups demonstrated the processes and value of co-construction between peers to enable communication abilities, and to develop preferred stories, identities and possibilities. This expands upon previous research highlighting the value of peer support for PWLD (Asquith, 2013) and indicates the value of the narrative theoretical lens to broaden understandings of how peer discussion may support change.

The analysis also highlighted the possibilities for interpretation of stories between those with and without dementia (e.g. interpretations where stories implicitly pointed to imagined possibilities). This supports Baldwin's (2006) contention that professionals may contribute to the narrative re-possession of PWLD, who have not in fact 'lost the plot' (pp. 105) but are often firmly in control of vividly telling their narratives, and may simply need opportunities, and at times facilitation, to re-author their stories.

4. FURTHER DISCUSSION AND IMPLICATIONS FOR PRACTICE

4.1. Critical Review and Limitations

Riessman (2008) argues that validity and ethics are the central evaluative concepts for narrative research, although there are no established criteria or procedures for validation suitable for all projects. These issues are complex, particularly in a dementia context, and I have aimed to address them transparently throughout, and expand with these concluding reflections.

4.1.1. Validity

4.1.1.1. Fostering 'trustworthiness'

Validity is evaluated through the 'trustworthiness' of the stories told, and the analytic story developed from them (Riessman, 2008), i.e., how well-grounded in data and supportable narrative research-generated knowledge claims are. To foster 'trustworthiness', I have attempted to produce a transparent written narrative of the research that reflects the chronological processes of my construction of the research topic and processes undertaken. Specifically, I have: transparently documented the processes by which I have recruited to, collected and interpreted data; analysed 'narratives in context' to include my role in co-construction with participants; presented myself as a situated, positioned author; and demonstrated how the findings led me to new perspectives and connections with the literature. For example, the research topic of 'dementia care' has developed through co-construction with the participants and reflexive reading of the literature to a shift in terminology to 'relational support'.

Whilst my interpretations are necessarily foregrounded in this academic thesis, I have also aimed to present a detailed yet open-ended account to invite participation in the interpretive and evaluative process.

4.1.1.2. External validity

Alongside pragmatic use (addressed below with concrete recommendations) Riessman (2008) argues that taking one's interpretations and conclusions back to participants strengthens trustworthiness of the research and credibility of findings, in addition to being ethically sound. Congruent with a social constructionist framework, taking stories back to participants was not intended to corroborate findings, but rather sought to determine whether my telling of their stories resonated with each, and to triangulate multiple interpretations, as opposed to a final 'truth' (Riessman, 2008). As with any single interpretation, including the researcher's, there are limitations as to what participant feedback can tell us. Memories and meanings of experiences may change over time (perhaps particularly so within a dementia context, some months after data collection), my theoretical accounts may not be meaningful to 'non-social scientists' (Riessman, 2008), and participants may simply disagree with my interpretations.

In practice, it was only the group members, diminished over several months to Pam, Mrs Kalil and George, who were able to contribute to the feedback. The ethical implications of only receiving feedback from some participants are explored further below. Selecting what to feedback constituted another form of interpretation, and for transparency Appendix 10 contains a written summary of what I chose to take to a meeting with the group, each of whom agreed that I could include their feedback in this written thesis.

There were nods of recognition and laughter as I read the narrative excerpts. All three participants strongly agreed that reciprocity was central to the support they value, within and outwith the IDS, and the functions of being in a group to build confidence and a sense of 'who you are'; Pam was particularly pleased regarding the example of how she supported Lionel in this.

The group expanded my understanding of the effects of the context of our research encounter. In response to my feedback about the relative absence of 'memory' and 'dementia' in the narratives, Mrs Kalil and George discussed how they do not see the IDS as a 'dementia service' but are aware that 'technically' it

is. Both told stories of stigma from others locally, and the association of the IDS with 'being loopy'. The feedback highlights the dangers of a single story (Ngozi Adichie, 2009) raising questions as to whether the group had successfully resisted undesirable identity constructions, or whether the research context had in some way precluded the narration of these undesirable identities.

4.1.1.3. Theoretical coherence and knowledge claims

The coherence of my interpretations constitutes a further validity test (Crossley, 2000). By this, I refer to whether sense has been made theoretically of convergence and divergence in the data, i.e. the consistency between the data and theory, within a framework of socially constructed knowledge, situated within the particular local contexts, (e.g. participants' individual life stories), and shared contexts (e.g. the historical context of this cohort of older adults, and of receiving dementia services in London in the early twenty-first century). Narrative data can contribute to empirically based theory; 'bottom-up' theorising of what sense people make of living with 'x' within 'context y' (Squire, 2013). Congruent with the research aims, these validity tests replace more traditional conceptualisations of 'generalisability', abstract rules and propositions.

Guided by broad research questions concerned with both what and how stories of dementia care were told enabled me to draw upon a breadth of theoretical frameworks for interpretation. My experience of the process of narrative analysis was that this enabled analysis to follow the data, with each group or individual account engendering particular foci. However, the potential roads that one might follow in interpretation was at times overwhelming. A key tension was between focus upon the shared contexts of participants and each individual's life stories. Both have consequences for how dementia care is made sense of, whilst, in my experience, the former is more easily theorised and summarised within a coherently social constructionist framework. My experience as both a researcher, and also as a clinician, is that there are as many 'theories' of experience as there are individual contexts – i.e. Squire's (2013) 'bottom up' theorising begins anew with each individual. Meeting participants over several occasions, observing the contexts of their lives – for example bumping into Lionel struggling alone with a

lost wallet on the bus home - developed my experience of each outside of the data. Having witnessed Lionel's social isolation as a material feature of his daily life does not preclude an understanding that this could be a consequence of the available social stories about the value of older people in current UK society, but does raise questions as to what has contributed to his particular experience.

Adhering to a single interpretive framework, such as Holloway and Jefferson's (2000) 'defended subjects', a psychoanalytic approach to narrative, might have produced a richer theoretical account of each individual. Alternatively, a primary focus upon the socio-cultural storylines drawn upon in the accounts of participants may have more fully elucidated the current discourses and the effects in current dementia care contexts. As it was, the integrated approach hints at, rather than fully explains, the range of possible influences upon the sense that PWLD make of themselves and dementia care experiences in the UK at present. In retrospect, an iterative approach to research, wherein the broad research questions were piloted and a preliminary analysis conducted to inform more specific questions (e.g. 'how do PWLD as storytellers negotiate the dilemmas of being labelled with dementia?') might have produced more tangible findings within a more coherent, albeit limited, theoretical framework. The time constraints of conducting this doctoral thesis in practice led to a process of simultaneously conducting the analysis and learning what knowledge claims are possible in the process.

In relation to the above challenges was the task of summarising the resultant research findings. Contextual meaning-making and theorising from individual accounts necessarily attends to divergence in the data. I have attempted to summarise the findings in relation to the research questions, focusing rather more on process than content – for example in relation to co-construction and individual sense-making between the past, present and future. This was congruent with the research aims to address the lack of evidence for the course and meaning of individual care experiences for PWLD in a particular socio-cultural context, and to offer something beyond the more frequently published research offering themes derived from dementia service evaluations. The resultant findings are therefore not easily summarised, but do, I would argue,

respond to a diversity of perspectives. This is particularly important in a dementia context in which perspectives of PWLD are seldom heard.

4.1.2. Ethical and methodological considerations

The research design, method and approach to analyses were intended to hold participant narratives as central. The contexts of dementia research, aims for a participatory component, the approach to narrative and preparation of the research to adhere to the requirements of an academic submission have presented methodological and ethical dilemmas, as outlined below.

4.1.2.1. Authorship and consent

Process-consent methods enabled responsiveness and an audit trail regarding consent to participate, with all consenting post-data collection for the inclusion of their contributions in the analysis and written report. Appendix 11 summarises however the incomplete process of ongoing feedback and contribution post-analysis.

This partial feedback to and from participants raises a dilemma in regards to ethical conduct as a researcher. Whilst adhering to guidance for good practice in dementia research (Dewing, 2007), I still struggled to balance responsiveness to participants' availability and wishes, whilst also working within a framework of fully informed consent and participation. I aim to continue to develop an ethical research relationship with participants via written summaries for each with contact details should they wish to contribute their opinion, or change their mind about inclusion. This is particularly important in the dementia context, although arguably also true for any research participant, where people may not remember telling their stories, and their consent to inclusion may change over time. I plan to include additional feedback in any subsequent publication, dissemination, etc., in this ongoing account.

Throughout data analysis I acted from a context of anticipation that participants would receive these interpretations, which guided me to work respectfully and

transparently, albeit from my own perspective. However, not everyone has been able to comment on what has been said about them, and those who did have not viewed this full report, only a selective summary. Consequently, I must conclude that limited participation post-data collection limits any claims of social empowerment and equity.

4.1.2.2. Power and 'participation'

Research which facilitates the stories of marginalised groups to be heard is not necessarily emancipatory (Elliot, 2005). This research has been an ongoing process of balancing my longstanding position in regards to a personal and political will to improve the lives of older people and PWLD, with genuinely listening and responding to the particular stories of the participants. There can be no doubt that, despite my intentions, this endeavour has reproduced existing power relationships for PWLD through the very act of my researching a group to which I do not belong. There are many dimensions to this dynamic, most notably related to age, cognitive ability and power (both structural and constructed in interaction), which I highlight here with an example.

Much of Flo's narrative was contextualised by her questioning the validity of her opinion, in a context of fear of further cuts to her care provision. Despite assurances of anonymity, what was her entitlement to criticise, or even comment, about a free service, when it is all that might be available? How entitled were participants to speak openly to a professional introduced to them via a service they receive? It is often a requirement of RECs that researchers are introduced to participants via services, which may link the researcher to a framework of feedback associated with consumerism and service efficiency.

Related to this, whilst no claims are made as to the 'representativeness' of the participants beyond the micro and macro contexts in which they are situated, concerns are raised as to the exclusion that gatekeepers may have exercised. In addition to concerns raised in the methodology regarding the uniform consent to participate, I approached another voluntary dementia organisation to expand recruitment and was denied access to service users without further discussion.

How can PWLD be held centrally to research processes when professionals exercise their right to determine access? Personhood and citizenship are at stake as service providers become experts on people, defined by 'dementia', rather than authorship of their own identity.

Participatory Action Research approaches aim for 'catalytic validity' (Lather, 1986) in which investigators work with communities from the inception of research through iterative cycles of action and research (Reason & Bradbury, 2001). In a dementia context this would likely relate to co-construction between people with and without labels of dementia.

4.2. Implications and Recommendations

From inception, this research has aimed to listen to PWLD with a view to expanding knowledge to inform dementia care provision. As outlined in the Introduction, this is in a context where user agendas, adequate provision, and coherent models of dementia care are lacking. The contribution of this research, which will be disseminated to the participating services, relevant local contexts in which I train and work as a CP, and more widely via conference presentation with a view to publication, is thus in developing a progressive research agenda, centring what is important for users alongside pragmatic recommendations for dementia support. Examples of support valued by PWLD are documented throughout the analysis and discussion; this section expands upon the implications.

I outline below how the key findings could be operationalised across health and social care practice, service development, and more broadly via leadership and policy, with a particular view to how CPs could contribute to this agenda, as expected from their roles (BPS, 2007; 2010).

4.2.1. The practice of CPs in 'dementia support' contexts

1. Narrative care

The findings in regards to the processes of co-construction demonstrated the value of support that facilitates opportunities for narrative expression and the enablement of personhood. Particularly evident was co-construction between peers to enable communication, develop preferred stories, identities and possibilities. Narrative approaches to therapy are theoretically well-established (e.g., White & Epston, 1990) and there is evidence of the approach in therapeutic work with individuals and families affected by dementia (e.g., Stott & Martin, 2010) as well as for a broader approach to 'narrative care' (*Ideas: Ageing by the Book*, 2014).

Inter-disciplinary approaches to narrative care include reading and responding to literature in groups and facilitating (co)authorship of personal stories. These aim to contribute to the co-construction of the self when physiological change and social responses to ageing and dementia challenge this, with stories developed over time to strengthen identities and build resilience (Kenyon, Bohlmeijer, & Randall, 2011). Working with stories invites shared practices – thereby addressing the loneliness narrated by some participants in the current research - alongside the narrative processes for change which are less reliant on cognitive ability, as responses are made in the moment (i.e., not reliant on memory).

In support of this recommendation, upon completion of data collection⁶ I facilitated and contributed to the generation of ideas for developing the IDS group, (e.g. a user forum and a peer support group) with the group opting to develop a reading circle. Meeting weekly, we read poems and short stories aloud, and I facilitated discussion in response using questions based upon White's (1997) 'outsider witnessing' practices to elicit connections, memories and emotions and, at times, possibilities for action. Group practices for reading aloud in the UK have been developed by the charitable social enterprise The Reader Organisation, which implements similar (although not explicitly theoretically

⁶ Clinical work was clearly demarcated from the research via verbal information and consent from each regarding group attendance. Membership was extended to all within the IDS.

grounded), groups across diverse settings including residential dementia care, for which there is a developing evidence base (Centre for Research into Reading, Information and Linguistic Systems, 2012).

CPs are well-placed to advance these practices by linking theory and practice and contributing to the evidence base to support their formal recognition and expand commissioning, for example, via NICE guidelines. Literature is only one medium to which people may respond and develop their sense of self and connectedness; there are also possibilities for using art, music and dance, etc.

To support this recommendation, training, ideally led by PWLD, regarding communication skills to enable personhood and narrative expression, such as pacing, acknowledging and contributing to people's preferred identities, is recommended.

2. Theory in practice: Formulating individualised support

In a context of 'person-centred' policy rhetoric yet poor operationalisation (Epp, 2003), the findings demonstrate the utility of the 'relationship to help' framework (Reder & Fredman, 1996) to make sense of, and respond to, interactions between diverse individual perspectives and life histories with the shared narratives and practices associated with dementia care. CPs are well placed to draw upon relevant formulation skills to guide truly individualised interventions and support plans. In practice this might be undertaken by CPs themselves, or CPs might train and supervise MDT colleagues in formulation skills to guide care planning, in collaboration with service users.

In response to the range of frames in which participants narrated their experiences (e.g. biomedical, ageing and social) support plans guided by formulations might continue to include combinations of physical, medical, social and psychological support. However, an individualised approach, with consideration to how support is responded to, would enable a more cohesive approach from care teams, and increase the likelihood of greater efficacy. This recommendation, alongside developments in evaluating outcomes, contributes to

addressing current concerns related to increased access to the diagnostic process in the absence of a strategic approach to care (Fox et al. 2013).

3. Collaboration and transparency in individualised support

The difficulties participants demonstrated in remaining within any one frame to narrate their dementia experiences, and the related effects upon identity constructions, supported the concerns raised in the introduction regarding the incoherence of current dementia models. Consequently, there is potential value in professionals collaborating with PWLD and their families to make sense of their experiences drawing upon what is (and is not) known in regards to dementia and effective interventions, and the individuals' priorities and values. This would enable PWLD (and their relatives/carers), to make informed choices about the support that they wish to take up and empower them in moving away from dependent 'patient' positions engendered by dementia models which lack clarity and evidence. Again, CPs are well placed to both directly facilitate collaborative care with clients, and consult, train and supervise with teams to develop this.

4.2.2. Service models for dementia support: Genuine local partnerships, interdependence and citizenship

In demonstrating the value of peer support (e.g. through the processes of co-constructing preferred identities and possibilities for action) and re-telling participants' narratives of the value of reciprocity across professional and informal contexts, this research provides academic evidence in support of pioneering examples of partnership practices (e.g. Dupuis et al, 2012). An example of such reciprocal partnership working in practice is UK pilot projects which have innovatively pooled individual personal care budgets of people over sixty (with and without dementia labels) to draw upon people's existing expertise to provide practical support, and social and cultural groups, alongside social care staff (*The Observer*, 2014: 34).

The findings regarding the political effects of dementia labels, being 'cared for' and 'researched' upon participants' rights and duties in authoring their stories, indicate the value of citizenship models. Service provision for people with

learning disabilities, another marginalised population, demonstrates a relatively recent history of advancing this agenda in policy and practice (e.g., DoH, 2009b), from which those developing dementia care may learn. For example, Carnaby (1999) demonstrates, via a cross-cultural comparison with Northern Italy, how interdependent living, reciprocity and peer-support via small shared homes for people with learning disabilities lead to outcomes including community integration, compared with UK practices of 'independent' living which contribute to social exclusion.

A citizenship model of dementia is an expansive topic which warrants further attention in collaboration with PWLD. As Patel (2003) argues, the role of the CP is to serve the populations with whom we work by privileging what they prioritise as their needs and using our skills and access to resources to enable change to occur on their terms. As supported by the processes undertaken during the consultation and during and after data collection with participants in this research, this might begin in local contexts with co-construction and facilitation of user agendas. Despite cuts to existing care provision, within the current political landscape there is potential to commission and provide care across contexts with user input (Health and Social Care Act, 2012).

Developing approaches to capacity and decision making is a concrete step towards attending to the politics of being labelled with dementia (Behuniak, 2010). As with the research methods demonstrated here, consent as an ongoing process, monitored and recorded, may be a useful step forward. This is possible within the remit of current legislation, and training with health and social care professionals is recommended.

As Baldwin (2008) argues, narrative is also linked to citizenship, in regards to the importance of narrative agency to author one's own stories and identities, and contribute to those of others. The above recommendations for narrative care, therefore, develop this agenda in practice.

4.2.3. Broader implications

Bartlett and O'Connor's (2007) call for dementia care concerned with equality of rights and compassion is anchored in the recognition that anyone may one day experience similar difficulties. This agenda reflects the range of participants' narratives (e.g. of love, survival, experience, mistrust and fear) better than current policy narratives of disease and burden. Increasing the availability of alternative, personal narratives may do much to alleviate public fears and stigma, and contribute to the re-valuing of this population in society. Dissemination of stories of experience is recommended, for example at MDT meetings to plan support, and through wider publication and consideration for policy and guidance. Pragmatism in linking this agenda to mainstream agendas, such as cost-effectiveness, and the broader 'compassionate care' agenda in the NHS, will likely be expedient and broaden recommendations to improve the quality and safety of care, such as the development of leadership cultures which place patient experience at the centre of care (Francis, 2013).

This research, and the subsequent narrative group at the IDS, also demonstrate the possibilities for eliciting and responding to user views with little resources or power. Beyond the limitations of a time-limited academic thesis, there are substantial possibilities for genuine long-term partnerships in research and action within local contexts.

4.2.4. Future research

1. *Process-consent methods* constituted good-practice guidance for the current research, yet require further development - as evidenced by the ethical and pragmatic tensions reflected upon throughout this thesis. Procedures are required to enable researchers to balance the safety and dignity of participants, alongside development to fully include traditionally marginalised populations in research, for example:

- As opposed to seeking the formal consent of carers to approach PWLD it is recommended that researchers maintain an audit trail of 'supporting observations' from people involved in the care of a participant.
- Researchers may serve their participants better if they challenge, perhaps collectively, restrictive ethics requirements that are often designed for medical research rather than in relation to asking the views of people who may have little other opportunity to author their own stories.
- Maintaining informed consent regarding what happens to people's contributions post-data collection requires improved transparency. For example, in retrospect it would have been helpful if I had asked participants how they would wish me to proceed in the event that their circumstances change.

2. *Progressive forms of user involvement, practice-based evidence and participatory research*, which acknowledge the politics of receiving services and 'being researched', and are concerned with democracy, rights and empowerment, are recommended for development with PWLD in response to the main findings (e.g. the effects of malignant positioning upon right to speak) and ethical limitations discussed here.

5. CONCLUSION

This social constructionist approach to narrative research with older PWLD offers evidence for the development of relational-support across peer, informal and professional networks and approaches to citizenship built upon narrative agency, compassion and inclusion. The research process and findings demonstrate both the limited identity constructions and possibilities available when people are defined as 'ill', 'cared-for' and 'researched' and the expansion of possibilities – as diverse as alleviating (the person's and our own) fears about ageing and memory loss and creative partnerships – when we join with people to whom we may previously not have listened and engage with what they have to tell us.

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APPENDICES

Appendix 1. Summary of literature review

Complete search terms with all synonyms:

(dementia OR dementia with Lewy bodies OR Alzheimer's Disease OR Vascular Dementia OR Frontotemporal dementia OR (Parkinson's disease AND dementia)⁷) AND (client attitudes OR client satisfaction OR client participation) AND (clinical practice OR day care centres OR quality of care OR quality of services OR telemedicine OR managed care OR Adult Day Care OR Elder Care OR primary care OR clinical psychology OR Home Care Personnel OR Allied Health Personnel OR Service Personnel OR Health Care Delivery OR home care OR social services OR health care services OR support groups OR residential care institutions OR integrated services OR community services OR interpersonal interaction OR respite care OR long term care OR nursing homes OR health personnel)

Inclusion criteria for studies in the review were:

- The participant sample includes people diagnosed with dementia
- The research topic is substantially related to professional dementia care, rather than informal caregiving
- Where other stakeholders views are included there is adequate inclusion of the perspective of the PWLD
- The study attempts to directly include the view of the PWLD

Excluded studies were:

- Studies which attempt to elicit the view of the PWLD by proxy
- Studies referring separately to search terms

^{7 7} MCI was not recognised in any database as a formal index term, although it may be included in the article text.

- Studies referring primarily to the diagnostic process⁸
- Research not written in English.

⁸ To enable a manageable scope for the current research the diagnostic process itself is not included in the definition of professional dementia care, although there may be some overlap with subsequent care received. This is also a pertinent topic for research, as for many people with dementia the diagnostic processes is the primary contact with professionals.

Appendix 2. Sample analysis excerpt

The below excerpt from the analysis of an interview transcript demonstrates how the integrated approach was undertaken. I attended to key narratives (relevant notes in black), broadening with re-reading to attend to positioning (relevant notes in brown) and broader context (relevant notes in green) to build the content and context of narratives across a transcript. The analytic process was the same for each encounter, group or interview, in addition to attending to key collective narratives, and co-construction in the group context. Throughout analysis, I attended to the extent to which narratives and contexts were shared or distinct across participants, as demonstrated in the Analysis and Discussion.

Please note that line numbers have altered slightly in the excerpt from original as font was enlarged for presentation here.

20 Tessa: So how, how do you find that relationship with your GP? Is it enough for you,
21 for your needs at the moment?

22 Sid: Well, I thought that if there was an alternative way of helping, he would have told
23 me. <Tessa: Right, umhm> You know, he would have either said 'you could go to
24 blah blah blah' <Tessa: umhm> and they would give you this and give you that,
25 which would slow the progress down, or make it better for you' <Tessa: yeah> But
26 that's as far as it's gone, just to tell ya <Tessa: ok> yes.

27 Tessa: And how's, your relationship with him, what's that like?

28 Sid: Oh quite good. I've been with him for years, y'know

29 Tessa: ok, good, ok

30 Sid: oh yeah, 'e knows my background from years ago, you know <Tessa: yeah>
31 and um, I've always found 'im quite good, y'know, he's always, and he's talkative,
32 you know what I mean?

33 Tessa: good, yeah

34 Sid: which is quite good, you know what I mean?

35 Tessa: Yeah

36 Sid: yeah, other than that y'know, it's um, that's all I've had really <Tessa:mmm>
37 with Alzheimer's

38 Tessa: and what about your contact with the Alzheimer's Society? Is that a café you
39 mentioned, a social or something? Is that something you go to?

40 Sid: Well, it's only, we only go to this social evening

41 Rose: First Thursday of the month

42 Sid: First Thursday of the month, and you get tea and cakes and that

43 Tessa: I think I've been to that, down at um, um,

44 Rose: [names street]

45 Tessa: Yes, yeah

46 Sid: Yes, we go to that every <Tessa: I went to that> to meet other people and
47 converse with each other. It's quite a pleasant event, you know what I mean? And it
48 gives you a break to get away from here. <Tessa: umm> [3]

49 Tessa: And how do you feel when you're there?

50 Sid: Well we 'ave our laughs and jokes, yknow what I mean? And er you converse
51 with other people that you've not met before, <Tessa: yeah> cos you sit on a

Commented [UTH1]: Again, assumes Dr knows what he's doing; strength of medical discourse, whilst hinting at possibility of wanting more... articulates that ideally this would involve slowing down or curing.

Commented [UTH2]: Trust with knowing over time (not just medical position, but relationship?)

Commented [UTH3]: Humanness valued too, and personal knowledge, not just medical.

Commented [UTH4]: Here and below Rose taking on same role with me and Sid, filling memory lapses. Only an extension of her natural role in helping/correcting, rather than feature of dementia caring?

Commented [UTH5]: Social role of services; and hints at potential isolation/lack of activity/ or even burden on rel'ships if needing 'break'?

Commented [UTH6]: E.g. of both social role, and possibly separates self from 'them'?

52 different, every time you go there you sit on a different table and you've got different
 53 people on the table <Tessa: yep> cos you've got about 4 or 5 on a table <Tessa:
 54 yep> and every week as you come in, you just go to the first table that's available
 55 <Tessa: that's nice> and the people that's on there, so you converse with them
 56 <Tessa: yeah> you know what I mean? <Tessa: yeah> and that's about all I know
 57 <Tessa: there's a few characters down there, isn't there?> (both laugh) and er, some
 58 are strange and some are, are ok (Tessa laughs) you know (both laugh)

59 Tessa: Same as anywhere I suppose (both laugh) And what about the staff there,
 60 how do you get on with them?

61 Sid: Quite good, yeah, <Tessa: mm> yeah they're very helpful down there, and
 62 they're always coming around looking if you want cakes, or tea or whatever, you
 63 know what I mean <Tessa: yeah> and it's quite good, it's quite good.

64 Tessa: and in terms of the memory side of things, does it help with that in any way?

65 Sid: Not really. [2]

66 Tessa: No

67 Sid: No. No. No, there's no talk about Alzheimer's at all, you know? Which could help
 68 you, or whatever. It's just a gathering, a meeting, and a little chat to each other

69 Tessa: Sure, ok [2] So in your mind, is there anything, a type of service that you
 70 could imagine that would be helpful at the moment?

71 Sid: Well, if I was advised by, you know the proper people that it could help, I would
 72 go there. But I'd have thought that the doctor would have said that all the same, you
 73 know what I mean?

74 Tessa: Yeah

75 Sid: Cos he's quite good, and I'm sure that he wouldn't neglect you if he felt that
 76 there was something else other than the tablets that would help you, I'd have thought
 77 he would have recommended <Tessa: yeah> it <Tessa: yeah> you know what I
 78 mean? <Tessa: yeah> But as far, as far as it goes, you know. Unless you know,
 79 another time he might, when I see him, he might suggest something, you know

80 Tessa: yeah, so it's a kind of waiting to see sort of process?

81 Sid: Well that's it, you know what I mean. Cos a lot of it's related to your age I
 82 suppose. You know I'm coming up to 84.

Commented [UTH7]: Enjoying showing knowledge with story of typical episode?

Commented [UTH8]: No association made with medical care/AD. Sees as caterers (I know the servers are actually Dementia Advisors etc)

Commented [UTH9]: Seemingly his 'real' opinion breaks through his being pleasant about things. Basically social support not really helping (COMBINES KEY NARRATIVE – DRAWS UPON MEDICAL DISCOURSE AS ONLY SOLUTION, AND POSITIONING AS GRATEFUL/YET MAYBE A BIT LET DOWN as expands below?)

Commented [UTH10]: EXTREMELY INFLUENCED BY MEDICAL DISCOURSE; SOCIAL FUNCTION OF SERVICES NOT VALUED BY ALL (perhaps as he has strong personal support networks?). Interesting how his opinion seeps out, actually as pleasant as it is it is, not at all helpful as seemingly nothing to do with AD.

Commented [UTH11]: Positions self at mercy of 'the proper people' telling him where to go; he is willing if they lead. Arguably a function of the strong policy message that we need a) diagnosis and b) to find a cure. Disempowered Sid to even consider whether he has any control over his situation; could lead to helplessness (although doesn't appear to have done as appears to have emotional and social support, even if he has not linked such to his current problem).

Commented [UTH12]: Absent but implicit is the possibility of neglect? Fears subtly conveyed. Could be both politeness/cohort effect affecting entitlement to speak. Or necessary to trust authorities to defend against fear/despair? Attempts hopefulness.

Commented [UTH13]: On surface, total faith in medics knowing what is best...but actually more complex as suggested above.

Commented [UTH14]: Links to ageing

Appendix 3. Consultation with PWLD

To consult with PWLD I developed links with an inner-London branch of the Alzheimer's Society, a leading support charity for PWLD, their families and carers. I visited a social group for PWLD and their carers, with approximately 25 people in attendance. The consultation group developed the conversational prompts for the research encounters, and advised on the research procedures to ensure that the research is relevant, understood and acceptable to PWLD.

On the following page is a copy of the summary of this consultation, which I fed back to the AS due to the wider relevance of inclusion of PWLD in service development. This highlights both the key decisions made by PWLD, such as the value of research encounters in both groups and one-to-one interviews, alongside my observations on process. For example, it was striking how difficult it was to elicit the voice of PWLD in the presence of carers. Carers attempted to protect their relatives from what they perceived as the stress of communication, with interventions such as "he won't understand that" when I asked for feedback on information sheets, alongside sharing their views that it is carers themselves who hold the information about what is helpful in the care of their relatives. Whilst acknowledging their position and the value of research with carers more broadly, I maintained a focus on talking with PWLD directly. Once allowed to do so, the feedback was clear, for example, in regards to requesting I talk them through the information sheets, the value of unstructured conversations and their ability to convey their views:

'Meet us where we're at on the day' (Beth⁹, consultant)

'Ask me; if it's reasonable I'll answer, if it's unreasonable, I'll tell you'. (Josiah, consultant)

⁹ Names of consultants changed for anonymity.

Consultation

Stories of professional care: Narrative analysis of accounts from people with dementia Feedback from [Service and event details]

Consultation Purpose

I was invited to the above event to consult directly with people with dementia to develop doctoral research regarding the care experiences of those with memory problems. Given current priorities for service user involvement, it is important that people with dementia be involved at every stage of the research process to ensure it is relevant and acceptable to them.

This was a one-off consultation regarding the proposed research questions and methods. Informal discussions were initiated to elicit views and advice on the proposed research. The event was attended by approximately 25 people affected by dementia, including carers. This was a lovely event for sharing in the community and the consultation has valuably informed how the research will be conducted.

What did I learn from the consultation?

The discussions highlighted the importance of research to hear the stories of people with memory problems. Also evident were carers' wishes to tell their stories and their views that they hold information about what is helpful. The event highlighted the value of both groups having space to tell their stories, and the importance of protecting space for those with memory problems to share their experiences, as their voices can be lost when others are present.

1. **Action point This research will focus on the stories of those with memory problems, told in settings where those with memory problems are the sole participants.**
2. **Action point Carers will be consulted regarding the participation of their relatives but will not participate in this research.**
3. **Action point. Separate research regarding the experiences of carers is also indicated, but will not be the focus of the current research.**

The majority of those I spoke to expressed a need for more information on what help is available for dementia, and what to expect in the future. Those affected expressed fear of deterioration and requested information from the researcher.

4. **Action points The researcher will have information/signposting available for participants if requested during research, e.g. Alzheimer's Society National Dementia Helpline 0300 222 1122**

Those consulted found the information sheets acceptable and accessible, both for carers and those with memory problem, who would like someone to go through it with them verbally.

All answered that a mixture of groups and 1:1 conversations are useful to talk about experiences for research purposes. People valued group as 'it triggers your own thoughts when you hear other people talking' and 'two heads are better than one'. However, 1:1 was valued for privacy and certain issues that they would not share in group.

5. **Action Point A combination of groups and 1:1 conversations is indicated for data collection.**

Those consulted agreed that the research questions were of value. They suggested acceptable and understandable examples of how best to phrase.

6. **Action Point Develop the ‘conversational prompt’ for participants using consultants’ examples, such as ‘Can you tell me about a time when you have received care from staff?’**

People generally thought that it was useful to have further prompts when and if needed, but first to see what happens and give space. Some helpful suggestions from consultants were *‘Meet us where we’re at on the day’* and *‘Ask me; if it’s reasonable I’ll answer, if it’s unreasonable, I’ll tell you’*.

Appendix 4. Transcription Conventions

[1] Pause, length in seconds

[Inaudible] Inaudible; approximate number of words or length of time specified

/ Interruption

(Laugh) Non-verbal utterance, or non-verbal observation (where used by participant to replace words only)

[name] name or place

<Tessa: text> Brief interjection/overlapping talk

... Text cleaned of brief utterances e.g. 'uh huh'; 'yeah' (in excerpts only)

[12-13] Transcript line numbers

Appendix 5. Guidance for Staff: Recruitment Procedure

Stories of care from staff: Accounts from people with memory problems

1. Staff at the recruitment sites will be asked to identify people meeting the inclusion criteria (overleaf).



2. Carers of those indicated as suitable for inclusion, who are usually involved in their relative's care decisions, will be provided with an information sheet and asked for written or verbal indication whether they know of any reason why their relative would object to, or experience distress when either being approached to discuss the research or participating in the research. In the absence of a relative involved in the care of the person with dementia, the researcher will work with staff to understand the usual ways the person would communicate consent or non-consent and record evidence of such.



3. If the above indicates it is acceptable, the researcher will meet the potential participant to invite them to partake in an initial conversation about the research.



4. A non-hurried consent meeting between the researcher and potential participant. The accessible illustrative information sheet will be provided to each potential participant. The information will be verbally explained, and consent to participation elicited verbally and behaviourally. The researcher will record written evidence of such.



5. The researcher will assess the individual's choice to continue participation throughout the research process, for example by monitoring behaviour and verbal utterances to assess frustration, tiredness, anxiety, etc., and asking whether the individual continues to assent to participation. The researcher will also ask consent to record group level demographic data, e.g. diagnostic status, service pathway, demographics (age, gender, ethnicity) which will not be attributed to individuals and used only in a summary table in the methodology of the report. Staff, carers and participants will be provided with contact details for the researcher for discussion or queries regarding participation throughout and upon completion

Inclusion Criteria for the research group

1. Participants must be in receipt of dementia care services as the primary service user, i.e. not as a carer of the person with dementia.
2. Ability to express oneself in English.

A particular type of care experience or level of cognitive ability are NOT prerequisites for inclusion. Those who do not demonstrate that they have understood the information about the group or verbally and behaviourally show consent upon meeting the researcher will not be included in the research.

All service users will be welcome to attend the subsequent dementia support group led by the researcher over the summer at the recruitment site. Participation in the research group is not related to this support.

Appendix 6. Example anonymised field diary

Field Notes.

Site: AS

Participant: 2c

Process Stage	Notes (Dated evidence, decisions made and action)
1. 'Permission to access' person with dementia from relative or staff	<p>Identified by support worker as interested and happy to be contacted. Lives alone.</p> <ul style="list-style-type: none"> - [Date] – Initial phone contact with 2c. He was unsure if he recalled conversation with his support worker but said 'I'm sure <i>[the dementia support worker]</i> mentioned it' and gave me permission to continue the conversation. He was interested in the research as I explained it verbally, and stated an interest in psychology, enjoying talking with 'educated people'. He agreed to a home visit to discuss what it would involve further, although had difficulty confirming date and address. Agreed I will discuss with his care-co-ordinator, whom he volunteered the name of, and arrange via them, sending a letter to confirm. Assured that he can change his mind and does not need to remember details of the conversation as I will put in writing. - [Date] Discussed with care co-ordinator, who advised to mail an appointment to 2c and call the day before to confirm. - [Date] Phone call from care-co-ordinator to advise of address change, 2c has received appointment letter and looking forward to meeting.
2. Record how person usually consents to care etc based on conversations with staff/relatives	<p>See above, based on conversations with 2c and care-coordinator, 2c verbally communicates his wishes in relation to his care. He does not have relatives/informal carers, but is supported by a community care co-ordinator to understand information, fill in forms etc. 2c does have significant memory problems; it is essential to seek consent on each occasion.</p>
3. Initial consent meeting, researcher and person with dementia, w/info sheets	<p><i>Include verbal and behavioural evidence of consent and checking of understanding. Record any discussions with staff/relatives regarding observations</i></p> <p>[Date] When I called 2c the day before our meeting to remind him, he referred to the info sheet he'd received in the post, and my picture, and was aware of my research role. He confirmed he would still like to participate in the meeting with me.</p> <p>[Date] 2c discussed with me what my role as a researcher as part of the Prof Doc involved, and we discussed the University of East London. 2c understood his anonymity, and he referred back to this to check it was maintained during the interview when he raised topics about which he did not wish the names to be disclosed. Clearly verbally consented to</p>

	<p>undertake the research interview today, including to record the interview, as confirmed on the audio-recording, and to include anonymous extracts. Also agreed his understanding to his right to withdraw at any time. He demonstrated his understanding of the research endeavour as he highlighted his wishes that the research has an outcome, as without such it is ‘a waste of time’. I discussed the hoped for value of the research in regards to recommendations for dementia care, fed back to participants, the recruitment sites and hopefully more widely in the literature/presentations etc.</p>
<p>4. Ongoing consent monitoring</p>	<p><i>Include verbal and behavioural evidence of continued consent or signs of distress (e.g. tiredness, frustration). Responses to asking if continue to consent.</i></p> <p><i>[Date, as above]</i> Ongoing consent is recorded on audio tape as 2c refers to particular issues about anonymity. 2c was clear about what was confidential and names not to mention in the report. I assured anonymity and agreed I will contact him post-analysis and, if he remains interested, feedback my findings to him to see what he thinks and include his input.</p> <p>2c was clear about what I could talk to his care-coordinator about when he disclosed a possible safeguarding issue during the interview. We discussed how he would like me to feed this back to care-coordinator and he outlined ‘you can thank him for introducing us, then softly, softly <i>[introduce the concern]</i>’. I advised 2c that I would follow this up with a conversation with his care-coordinator. When I spoke to the care-coordinator he was aware of the situation referred to and continues to address it with 2c.</p> <p>Interview ended when the cleaner entered 2c’s room unannounced. I stopped the tape recorder as we agreed to end the conversation to protect privacy. 2c thought he had said all he wished to on the subject anyway.</p>
<p>5. Consent upon completion to use data</p>	<p>Yes, see above. Understood and mentioned research he sees in the paper that do not result in any action, so urged results acted upon. We discussed how the research will be used again.</p>
<p>6. Consent to collect group level demographics</p>	<p>Yes, agreed I would do so via care-coordinator.</p>
<p>7. Any feedback, including staff/relative’s feedback during or upon completion.</p>	<p><i>[Date]</i> Phone conversation with care-coordinator who saw 2c at home the same day as interview. 2c told him that he had taken part in a study and that what we had talked about would ‘be taken back to that’. Confirmed I will be in touch in the spring to seek/give feedback.</p>

Appendix 7. Overview of the Process Consent Model (based on Dewing, 2007)

1. *Establishing Basis for Consent:* Staff at the recruitment sites will be asked to identify people meeting the inclusion criteria.

Proxy consent will not be obtained on behalf of the participant. However, in accordance with good practice, (Allan, 2001), for those who usually involve a carer in their decision making, the carer will be provided with an information sheet (Appendix 8) and asked for written or verbal indication as to whether they know of any reason why their relative would object to, or experience distress when either being approached to discuss research or participating.

In the absence of a relative involved in the care of the person with dementia, the researcher will work with staff to understand the usual ways the person would communicate consent or non-consent and record evidence of such.

If the above indicates it is acceptable, the researcher will meet the potential participant to invite them to partake in an initial conversation about the research.

2. *Initial Consent:* A non-hurried consent meeting between the researcher and potential participant. A standard, accessible illustrative information sheet based on that used by Allan (2001) and deemed acceptable by consultants with dementia (Appendix 8) will be provided to each potential participant. The information will be verbally explained, and consent to participation elicited verbally and behaviourally, with reflexive checking by the researcher of understanding and consent.

Field notes will be maintained by the researcher and observations discussed with care staff and family to contribute to the information available to aid the informed-consent process. This is an alternative to seeking written consent from the participant which in the context of dementia may be unreliable and may create anxiety, for example, people may remember signing an official form, but not recall why.

3. *Ongoing consent monitoring*: Assessment of the individual's choice to continue participation is proposed to ensure the ethical framework is maintained.

Examples of how this will be achieved include the researcher's monitoring of non-verbal behaviours and verbal utterances to assess frustration, tiredness, anxiety, etc., and asking both when these cues indicate distress, and at regular intervals in the interview process, whether the individual continues to assent to participation and/or would like to re-schedule to complete the interview. The researcher will also again ask for consent to use the data collected for analysis and write-up on completion of the interview. The researcher will also ask consent to record group level demographic data, e.g. diagnostic status, service pathway, demographics (age, gender, ethnicity) which will be used only in a summary table in the methodology of the report. Staff, carers and participants will be provided with contact details for the researcher for discussion or queries regarding participation throughout and upon completion

Staff will be provided contact details of the researcher to ensure feedback can be made should the individual and/or carers raise concerns about participation once the researcher has left

4. *Support*: Dewing (2007) notes that this process method is reliant on the researcher's critical reflection and skills to interact with the person with dementia, which in this research is supported by the researcher's clinical experience and supervision.

Appendix 8. Ethics application, including information sheets, and approval granted by the University of East London Research Ethics Committee

UNIVERSITY OF EAST LONDON School of Psychology

APPLICATION FOR RESEARCH ETHICS APPROVAL FOR RESEARCH INVOLVING HUMAN PARTICIPANTS

FOR PROFESSIONAL DOCTORATE RESEARCH IN CLINICAL, COUNSELLING & EDUCATIONAL PSYCHOLOGY

Students on the Professional Doctorate in Occupational & Organisational Psychology and PhD candidates should apply for research ethics approval through *Quality Assurance & Enhancement* at UEL and NOT use this form. Go to: <http://www.uel.ac.uk/qa/research/index.htm>

Before completing this form please familiarise yourself with the latest *Code of Ethics and Conduct* produced by the British Psychological Society (BPS) in August 2009. This can be found in the Professional Doctorate Ethics folder on the Psychology Noticeboard (UEL Plus) and also on the BPS website www.bps.org.uk under *Ethics & Standards*. Please pay particular attention to the broad ethical principles of respect and responsibility.

HOW TO COMPLETE & SUBMIT THE APPLICATION

1. Complete this application form electronically, fully and accurately.
2. Type your name in the 'student's signature' section (5.1).
3. Include copies of all necessary attachments in the **ONE DOCUMENT SAVED AS .doc**. See page 2
4. Email your supervisor (Director of Studies) the completed application and all attachments as **ONE DOCUMENT**. INDICATE 'ETHICS SUBMISSION' IN THE SUBJECT FIELD OF THIS EMAIL so your supervisor can readily identify its content. Your supervisor will then look over your application.
5. If your application satisfies ethical protocol, your supervisor will type in his/her name in the 'supervisor's signature' section (5.2) and email your application to the Helpdesk for processing. You will be copied into this email so that you know your application has been submitted. It is the responsibility of students to check this. Students are not able to email applications directly to the

Helpdesk themselves.

6. Your supervisor will let you know the outcome of your application. Recruitment and data collection are NOT to commence until your UEL ethics application has been approved, along with other research ethics approvals that may be necessary (See 4.1)

MANDATORY ATTACHMENTS

1. A copy of the invitation letter or text that you intend giving to potential participants.
2. A copy of the consent form or text that you intend giving to participants.

OTHER ATTACHMENTS AS APPROPRIATE

- A copy of original tests and questionnaire(s) and test(s) that you intend to use. Please note that copies of copyrighted (or pre-validated) questionnaires and tests do NOT need to be attached to this application. Only provide copies of questionnaires, tests and other stimuli that are original (i.e. ones you have written or made yourself). If you are using pre-validated questionnaires and tests and other copyrighted stimuli (e.g. visual material), make sure that these are suitable for the age group of your intended participants.
- A copy of the kinds of interview questions you intend to ask participants.
- A copy of ethical clearance from an external organisation if you need one, and have one (e.g. NHS ethical clearance). Note that your UEL ethics application can be submitted and approved before ethical approval is obtained from another organisation, if you need this (see 4.1). Please confirm with your supervisor when you have external ethical clearance, if you need it.
- CRB clearance is necessary if your research involves 'children' (anyone under 18 years of age) or 'vulnerable' adults (see 4.2 for a broad definition of this). Because all students registered on doctorate programmes in clinical, counselling or educational psychology have obtained a CRB certificate through UEL, or had one verified by UEL, when registering on a programme, this CRB clearance will be accepted for the purpose of your research ethics application. You are therefore not required to attach a copy of a CRB certificate to this application.

*** IF SCANNING ATTACHMENTS IS NECESSARY BUT NOT AT ALL POSSIBLE, SUBMIT TWO HARDCOPIES OF YOUR APPLICATION (INCLUDING ALL ATTACHMENTS) DIRECTLY TO THE HELPDESK. HARDCOPY APPLICATIONS ARE TO BE SIGNED BY YOU AND YOUR SUPERVISOR AND DELIVERED TO THE HELPDESK BY YOU**

N.B: ELECTRONIC SUBMISSION IS REQUIRED WHERE AT ALL POSSIBLE AS HARDCOPY SUBMISSION WILL SLOW DOWN THE APPROVAL PROCESS

REMEMBER TO INCLUDE ALL NECESSARY ATTACHMENTS IN THE ONE APPLICATION DOCUMENT AND EMAIL THE COMPLETE APPLICATION AS ONE DOCUMENT (.doc) TO YOUR SUPERVISOR WITH 'ETHICS SUBMISSION' IN THE SUBJECT FIELD OF YOUR EMAIL

1. Initial details

1.1. Title of Professional Doctorate programme:

Professional Doctorate in Clinical Psychology

1.2. Registered title of thesis:

Stories of professional care: Narrative analysis of accounts from people with dementia

2. About the research

2.1. Aim of the research:

The proposed research aims to elicit individual narrative accounts by people with dementia regarding their professional care experiences. The aim of such research is “to understand something of each individual’s perspective” (Proctor 2001, p. 361) and of the interaction between individual and collective narratives. The broad research questions are: What stories of professional care do people with dementia tell? Within this telling, are there hints of how people position themselves through the narratives told, and how sense is made of care experiences by the individual? Further, what are the implications in relation to what care they value or would value? An initial consultation with people with dementia will inform specific issue(s) that are deemed relevant, clear and acceptable to this group in relation to the research questions.

2.2. Likely duration of the data collection/fieldwork from starting to finishing date:

The estimated data collection period is April 2013 – April 2014. Data collection will commence with Alzheimer’s Society [name of branch] on receipt of UEL ethical clearance. Data collection with the Integrated Dementia Day Services in [name of borough] will commence following receipt of Social Care REC approval, estimated from April 2013.

The consultation group with people with dementia from Alzheimer’s Society is planned for March 2013. This does not constitute research participation; those involved will hold an advisory role to the project for the period of attending the consultation meeting.

Methods. (Please give full details under each of the relevant headings)

2.3. Design of the research:

Approach to data collection

The proposed approach to this research is to undertake qualitative research in the form of unstructured interviews, or ‘purposeful conversations’ (Burgess, 1988). Killick (2001) suggests that direct questioning with this group can lead to anxiety and confusion and suggests instead time and encouragement to ‘tease out’ their perspectives which may be represented in narrative form.

Interview Procedure

The 'interviews' will entail conversations following a uniform opening question or conversational prompt to elicit the stories of the person with dementia in relation to professional care. As in Montague's (2005) research of relationships in talk amongst older women, it is proposed that each conversation will assume its own pattern.

Duration and pacing of interviews should be dictated by the interviewee to avoid tiredness and anxiety and will be informed by each interaction with participants. If preferred by participants, additional meetings will be offered.

Interviews will be audio-recorded and transcribed by the researcher for analysis. Each participant will be asked if and how they would like contribution to, or feedback from, the analysis.

2.4. Data Sources or Participants:

Recruitment

People with dementia will be recruited through identified social care and voluntary sector organisations, links with which have been made and permission sought and agreed with service leads (pending application and receipt of ethical clearance). The identified recruitment sites are the local authority led Integrated Dementia Day Services in [name of borough], and Alzheimer's Society [name of branch]. This is not a comparative study; the aim is to consider professional care experiences broadly. Participants will be recruited separately from the consultation group. Either 6-9 individual interviews or a group discussion alongside four individual interviews will be conducted for data collection, dependent on the consultation group advice.

Inclusion Criteria

Participants must be in receipt of dementia care services as the primary service user, i.e. not as a carer of the person with dementia. An ability to express oneself in English is required to enable the researcher, an English speaker, to undertake a thorough narrative analysis of the transcripts. A particular type of care experience or level of cognitive ability are not pre-requisites for inclusion.

2.5. Measures, Materials or Equipment:

There is no formal interview schedule, rather the 'interviews' will entail conversations following a uniform opening question or conversational prompt to elicit the stories of the person with dementia in relation to professional care.

Audio recording equipment owned by the researcher will be used in data collection. Recordings will be immediately transferred to a password protected computer file and deleted from the device. Transcription software to be loaned from the Psychology Helpdesk.

The researcher is to keep an anonymised, confidential field diary as per informed consent procedure, below.

Information sheets and a consent form are to be prepared, see below.

If you are using copyrighted/pre-validated questionnaires, tests or other stimuli that you have not written or made yourself, are these questionnaires and tests suitable for the age group of your participants?

N/A

2.6. Outline of procedure, giving sufficient detail about what is involved in the research:

(Outline the stages of the proposed research from sending out participant invitation letters and gaining consent through

to what will be involved in data collection/experimentation/interview. For example, what will participants be asked to do, where, and for how long?)

Establishing Basis for Consent/Recruitment. Based on good practice recommendations from Dewing (2007).

Staff at the recruitment sites will be asked to identify people meeting the inclusion criteria.

Rather than obtain proxy consent on behalf of participants, carers will be provided with an information sheet (see below) and asked for written indication whether they know of any reason why their relative would object to, or experience distress, when either being approached to discuss research or participating (see Information Sheets and form attached at end of document, in line with recommendations for participation in dementia research from Allan (2001). In the absence of a relative involved in the care of the person with dementia, the researcher will work with staff to understand the usual ways the person would communicate consent or non-consent and record evidence of such.

If the above indicates it is acceptable, the researcher will meet the potential participant to invite them to partake in an initial conversation about the research.

Initial Consent

A non-hurried consent meeting between the researcher and potential participant. A standard, accessible illustrative information sheet based on that used by Allan (2001) (below) will be provided to each potential participant. The information will be verbally explained, and consent to participation elicited verbally and behaviourally, with reflexive checking by the researcher of understanding and consent. Field notes will be maintained by the researcher and observations discussed with care staff and family to contribute to the information available to aid the informed-consent process. This is an alternative to seeking written consent from the participant which in the context of dementia may be unreliable and may create anxiety, for example, people may remember signing an official form, but not recall why.

Interview Procedure

Data collection will take place at venues deemed acceptable to participants; this is likely to include private rooms at the recruitment sites and home visits. For safety the researcher will let recruitment site collaborators know when and where each interview is being conducted.

The 'interviews' will entail conversations following a uniform opening question or conversational prompt to elicit the stories of the person with dementia in relation to professional care. As in Montague's (2005) research of relationships in talk amongst older women, it is proposed that each conversation will assume its own pattern.

Duration and pacing of interviews should be dictated by the interviewee to avoid tiredness and anxiety (Clarke and Keady, 1996) and will be informed by each interaction with participants. If preferred by participants, additional meetings will be offered. Interviews will be audio-recorded and transcribed by the researcher for analysis.

Each participant will be asked if and how they would like contribution to, or feedback from, the analysis.

Ongoing consent monitoring

Assessment of the individual's choice to continue participation is proposed to ensure the ethical framework is maintained. Examples of how this will be achieved include the researcher's monitoring of non-verbal behaviours and verbal utterances to assess frustration, tiredness, anxiety, etc., and asking both when these cues indicate distress, and at regular intervals in the interview process, whether the individual continues to assent to participation and/or would like to re-schedule to complete the interview. The researcher will also again ask for consent to use the data collected for analysis and write-up on completion of the interview. Staff will be provided contact details of the researcher to ensure feedback can be made should the individual

and/or carers raise concerns about participation once the researcher has left.

3. Ethical considerations

Please describe briefly how each of the ethical considerations below will be addressed.

(See the BPS guidelines for reference, particularly pages 10 & 18, and the step-by-step guide in the Prof Doc Ethics folder)

3.1. Obtaining fully informed consent:

This is a serious consideration for this research. Please refer to the process consent method, based on Dewing (2007) outlined above. The processes outlined above are congruent with the aims of the MCA (2005) to aid people to make their own decisions. A diagnosis of dementia does not necessarily indicate incapacity to consent to research involvement, rather capacity to consent is largely situational and complexity dependent (MCA, 2005; Dewing, 2007).

McKeown, Clarke, Ingleton and Repper (2010) reviewed examples of good practice in dementia research and offer guidance on how to actively involve people with dementia within an ethical framework. The authors recommend process consent methods, as outlined above, whilst the Mental Capacity Act (MCA, 2005) provides a guiding framework.

Support

The process consent method is reliant on the researcher's critical reflection and skills to interact with the person with dementia, which in this proposal is supported by the researcher's clinical experience and identified supervision from a clinical psychologist at UEL and at the IDS site.

3.2. Engaging in deception, if relevant: (What will participants be told about the nature of the research?)

The proposed research involves no deception.

3.3. Right of withdrawal:

Please refer to process consent method above for details of how this is communicated to participants through ongoing consent processes. Participants will be advised of their right to withdraw from the research study at any time without disadvantage to them and without being obliged to give any reason. This is made clear in the information sheet (below). The researcher will again ask for consent to use the data collected for analysis and write-up on completion of the interview and if consent is withheld the data will not be used in the analysis and the recording deleted.

3.4. Anonymity & confidentiality: (Please answer the following questions)

Will the data be gathered anonymously (i.e. will you know the names and contact details of your participants?)

NO

If NO, what steps will be taken to ensure confidentiality and protect the identity of participants?

The researcher will transcribe the interview and/or group data. All transcripts and field notes will be fully anonymised, including quotations used in the written thesis and any subsequent publication.

Digital records and anonymised transcribed materials will be stored electronically and password protected at

the file and computer level and digital records will be erased upon conclusion of examination of the research.

Anonymity will be maintained by assigning each participant a code and changing all names and identifying references. Anonymised transcripts will be held by the researcher for up to a period of 5 years to enable use for subsequent publications of the research findings.

The assigned codes and carer forms will be kept in a locked cabinet at the respective collaborating sites, separate from the data collected. Access to anonymised transcripts is limited to the researcher, supervisors, and examiners.

The researcher will maintain confidentiality of what is said by participants in research interviews and groups. This confidentiality will be broken, in discussion with supervisors, only if the researcher has concerns about the safety of a participant or others, and local safety protocols followed. Where possible the researcher will discuss this with the individual before confidentiality is broken. The above will be communicated to participants via information sheets, as shown below.

3.5. Protection of participants:

(E.g. Are there any potential hazards to participants or any risk of accident or injury to them? What is the nature of these hazards or risks? How will the safety and well-being of participants be ensured? What contact details of an appropriate support organisation or agency will be made available to participants, particularly if the research is of a sensitive or potentially distressing nature?)

There are no potential risks or hazards identified to participants beyond the potential tiredness, anxiety or confusion which is addressed in the above detailed procedures, process consent methods and confidentiality above.

3.6. Will medical after-care be necessary?

NO

If YES, give reasons and outline what provision has been made/will be made for this?

3.7. Protection of the researcher:

(E.g. Will you be knowingly exposed to any health and safety risks? If equipment is being used is there any risk of accident or injury? If interviewing participants in their homes will a third party be told of place and time and when you have left the house?)

In regards to home visits, for safety the researcher will let recruitment site collaborators know when and where each interview is being conducted and use a mobile phone to let that person know when the interview is completed and the home is left. A risk assessment for the interviews has been completed at registration.

3.8. Debriefing:

(E.g. Will participants be informed about the true nature of the research if they are not told beforehand? Will participants be given time at the end of the experiment/interview to ask you questions or raise concerns? Will they be re-assured about what will happen to their data/interview material?)

Again, please refer to the process consent methods outlined above. Additionally, the interview procedure will be augmented by the period leading to this in allowing the individual to relax and feel respected as an individual, and for this to continue after the recording has ended, such as through cups of coffee and chatting to reduce the possibility of the participant feeling used, alongside allowing the researcher to observe verbal and behavioural feedback for signs of distress or withdrawal of consent.

3.9. Will participants be paid?

NO

If YES: How much will participants be paid and in what form (e.g. cash or vouchers?)

Why is payment being made and how has the amount specified above been calculated?

3.10. Other:

(Is there anything else the assessor of this application needs to know to make a properly informed assessment? E.g. if you are researching overseas have you stated where and outlined possible risks and what you will do to safeguard yourself?)

N/A

4. Other permissions and clearances

4.1. Is ethical clearance required from any other ethics committee? YES

If YES, please give the name and address of the organisation:

An application will be made to the Social Care REC for approval via the 'Integrated Research Application System' (IRAS) at <https://www.myresearchproject.org.uk/>. Ethical clearance via the IRAS system is sought for the data collection component planned with local authority led IDS, located at the below addresses:

[IDS address]

Has such ethical clearance been obtained yet? NO

If NO, why not?

The application for ethical approval is being made simultaneously to IRAS. The Director of Studies remains informed as to its progress.

PLEASE NOTE: UEL ethical approval can be gained before approval from another research ethics committee is obtained. However, recruitment and data collection are NOT to commence until your research has been approved by UEL and other ethics committees as may be necessary. Please let your supervisor know when you have obtained ethics approval from another organisation, if you need one.

4.2. Will your research involve working with children or vulnerable adults? * YES

If YES, please tick here to confirm that you obtained a CRB certificate through UEL, or had one verified by UEL, when you registered on your Professional Doctorate programme.

☒

If your research involves young people between the ages of 16 and 18 will parental/guardian consent be obtained. N/A

* 'Vulnerable' adult groups include people aged 18 and over with psychiatric illnesses, people who receive domestic care, elderly people (particularly those in nursing homes), people in palliative care, people living in institutions and sheltered accommodation, for example. Vulnerable people are understood to be persons who are not necessarily able to freely consent to participating in your research, or who may find it difficult to withhold consent. If in doubt about the extent of the vulnerability of your intended participant group, speak to your supervisor.

References:

Allan, K. (2001). *Communication and consultation: Exploring ways for staff to involve people with dementia in delivering services*. Bristol: The Policy Press.

Burgess, R. (1988). Conversations with a purpose: the ethnographic interview in educational research. In R. Burgess (ed.) *Studies in Qualitative Methodology: A Research Annual* (pp. 137-156). London: Jai Press Inc.

Clarke, C.L. and Keady, J. (1996). Researching dementia care and family caregiving - extending ethical responsibilities. *Health Care in Later Life*, 1(2), 85-95.

Dewing, J. (2007) Participatory research: a method for process consent with persons who have dementia. *Dementia*, 6, 11 – 25.

Killick, J. (2001) 'The best way to improve this place' – gathering views informally. In C. Murphy, J. Killick & K. Allan (eds). *Hearing the User's Voice: Encouraging People with Dementia to Reflect on their Experiences of Services* (pp. 6–9). Stirling: Dementia Services Development Centre.

McKeown, J., Clarke, A., Ingleton, C. and Repper, J. (2010). Actively involving people with dementia in qualitative research, *Journal of Clinical Nursing*, 19, 1935–1943.

Mental Capacity Act 2005 (c.9) London: HMSO

Montague, J. (2005). Researching relationships in talk amongst women who are personally connected. In C. Holland (ed.). *Recruitment and Sampling: Qualitative Research with Older People* (pp.14 – 28). London: Centre for Policy on Ageing.

Proctor, G. (2001). Listening to Older Women with Dementia: relationships, voices and power. *Disability & Society*, 16(3), 361-376.

5. Signatures

ELECTRONICALLY TYPED NAMES WILL BE ACCEPTED AS SIGNATURES BUT ONLY IF THE APPLICATION IS EMAILED TO THE HELPDESK BY YOUR SUPERVISOR

5.1. Declaration by student:

I confirm that I have discussed the ethics and feasibility of this research proposal with my supervisor(s).

I undertake to abide by accepted ethical principles and appropriate code of conduct in carrying out this proposed research. Personal data will be treated in the strictest confidence and participants will be fully informed about the nature of the research, what will happen to their data, and any possible risks to them.

Participants will be informed that they are in no way obliged to volunteer, should not feel coerced, and that they may withdraw from the study without disadvantage to themselves and without being obliged to give any reason.

Student's name: Tessa Hughes

Student's signature: T.Hughes

Student's number: U1138185

Date: 01/03/13

5.2. Declaration by supervisor:

I confirm that, in my opinion, the proposed study constitutes a suitable test of the research question and is both feasible and ethical.

Supervisor's name: Dr Maria Castro

Supervisor's signature: Maria Castro

Date: 12.03.13

PLEASE CONTINUE THE APPLICATION ON THIS SAME DOCUMENT

Please note that all information sheets and forms on the forthcoming pages have been subject to consultation with people with memory problems and their carers/relatives. The materials were initially derived based on the clinical experience of the researcher and Director of Studies, and examples of good practice from previous research (Allan, 2001).

Following Pages: PARTICIPANT and RELATIVE INVITATION LETTER, and FORM FOR RELATIVES

Stories of care from staff: Accounts from people with memory problems

Information for relatives (Version for group)

This project aims to listen to people's experiences and feelings about care from staff. I am interested to speak to people who have a memory problem and have received any type of care from staff as a result of this.

I would like to find out about how being cared for by professionals has been for your relative. I think this is important so that people's experiences can be taken into account when people like psychologists plan care services for people with memory problems.

People with memory problems are often not asked their opinions in research. There are various reasons for this, for example when people do have memory problems they may not be able to remember what care they have received. More recently however, workers, carers and researchers in this area have come to realise that people who have memory problems are able to communicate their feelings and experiences.

My name is Tessa Hughes



I work for the NHS and I am training as a Clinical Psychologist. I will be doing this research as part of my Professional Doctorate in Clinical Psychology at the University of East London. Contact Telephone: xxxxx Email: xxxx

Information for relatives

The purpose of this leaflet is to provide you with the information that you need to be able to decide whether you have any objections to Tessa approaching your relative to have a conversation about the research, or to your relative participating in the research.

How would the research involve my relative?

Group conversations with Tessa



If relatives are happy for Tessa to do so, she will meet with the person with memory problems to explain the research using a leaflet similar to this one. By taking the time to talk with your relative and listen to and observe their responses Tessa will explore whether they have understood and would like to be involved in the research.

If the person agrees to involvement in the research:

- Tessa will invite your relative to a group conversation at [name of IDS], arranged at a time when they would usually attend the service.
- The group will involve a conversation between Tessa and a group of service users who have consented to join the research.
- Tessa will start the conversation with a question about the group members' stories of care, and what people talk about will be decided by them. It might include stories of care they have received and what they have liked or not liked about this, or it might be more general talk about their feelings around care.
- Tessa will check with people how long they feel happy to talk for and stop if they need a break or have done enough talking. The group can meet more than once to finish the conversation, if people prefer to.

We understand that sometimes a person with memory problems can become frustrated or upset. Tessa will pace the talking to ensure that your relative is not put under stress. If they do become upset, she will stop at once and offer reassurance and comfort.

The group will be audio-recorded by Tessa. This is because everything people say will be carefully considered. The recording is instead of taking notes. Only Tessa will listen to the recordings. She will then produce an anonymised written record of the conversation. This means that nothing said will be identified to your relative.



Tessa will write a report to tell other people what she has found out from the conversations in general. This report will include quotes of particular things individuals have said in the conversations. It will not use anyone's real name or any information to identify people.

If you have any other questions, please talk to Tessa or a member of staff. You may contact the researcher using the above details with any queries or concerns.

If there are no objections from relatives, it will be entirely the decision of each person whether they wish to take part.

If you do object to your relative being approached, or they do not want to take part, that is alright. They will not be asked to give a reason if they do not want to take part.

If they start and decide that they want to stop they are free to do so.

Whatever you and your relative decide about taking part, this will not affect the help you get here or anywhere else.

Thank you very much for your time

Confidentiality of the Data



Anonymised recordings and written versions of the conversations will be kept safe. Your relative's name and details will NOT be stored. A note will be made of who has taken part and kept separately and safely at [name of IDS] along with the enclosed form if you choose to sign it.

The recordings will be deleted following the examination of the research. The anonymous written versions will be kept for up to five years as they may help with future work.

Tessa will keep anonymous notes of all her contact with people involved in the research. Access to these notes is limited to the researcher, supervisors, and examiners.

If during our conversations Tessa is worried about your relative's, or anyone else's safety, she might need to share this with other people to ensure people remain safe. Tessa will always try and let your relative know if this was going to happen.

If you have any questions or concerns about how the study has been conducted, please contact the study's supervisor, Dr Maria Castro.

Address: xxxxxxxx

Telephone: xxxxxx

Email: xxxxxxxxxx

Form for relatives

Research Study: Stories of care from staff: Accounts from people with memory problems

This form asks you some questions about your knowledge of the above project. It also asks you questions based on your knowledge of your relative

Your name (block capitals)

The name of your relative

Your relationship to the above person

Please answer the questions by ticking one of the boxes.

- **I have a copy of the leaflet giving information about the project.**

YES ☐

NO ☐

- **I understand that I can ask for more information from staff in [name of IDS]
or from the researcher, Tessa Hughes**

YES ☐

NO ☐

- **I confirm that I know of no reason why my relative would object to *being approached*
to take part in the project.**

YES ☐

NO ☐

- **I confirm that I know of no reason why my relative would object to *actually* taking part.**

YES ☐

NO

- I confirm that I know of no reason why my relative would be negatively affected by taking part.

YES ☐

NO ☐

- I understand that the decision to participate or not would not affect any help they receive now or in the future.

YES ☐

NO ☐

Now please check that you have answered all the questions. If you have answered 'yes' to all the above questions please sign below

Signature.....

Date.....

Thank you for your time. It is greatly appreciated.

Stories of care from staff: Accounts from people with memory problems¹⁰

I am interested in listening to people who have a memory problem and their experiences and feelings about care from staff.

I think this is important so that your experiences can be taken into account when people like psychologists plan services for people with memory problems.

My name is Tessa Hughes



I work for the NHS and I am training as a Clinical Psychologist.

I will be doing this research as part of my Professional Doctorate in Clinical Psychology at the University of East London.

Contact Telephone: xxxxxx Email: xxxxxxxx

Requesting your Consent to Participate in the Research

The purpose of this leaflet is to provide you with the information that you need to consider to decide whether to participate in this research.

¹⁰ Based on advice from consultants the written information did not refer to 'dementia' but 'memory problems' as this was congruent with their self-definitions. In conversation with participants, the researcher followed the terminology used by each individual, which for some was dementia or formal diagnoses, such as Alzheimer's. This was congruent with good practice examples, such as Allan (2001), who also recognised that 'memory problems' may be criticised as euphemistic, but that it is not within the scope of research to challenge people's understanding of their situation.

Conversations with Tessa



If you would like to take part, Tessa will have a conversation with you.

Tessa will start the conversation with a general question about your experiences of support from staff.

What you talk about will be decided by you. It might include stories of care you have received and what you have liked or not liked about this.

Tessa will check with you how long you feel happy to talk for and stop if you need a break or have done enough talking.

If you prefer, you can meet with Tessa more than once to finish the conversation.

Tessa will ask where you would like to have the conversation and meet with you there. This could be at a private room at [name of voluntary service] or a visit to you at home if you prefer.

The conversation will be audio-recorded by Tessa. This is because everything you say will be carefully considered. Only Tessa will listen to the recordings. She will then produce an anonymised written record of the conversation. This means that nothing you say will be identified to your name.



Next year Tessa will write a report to tell other people what she has found out from the conversations. This report might include some of the things you have said in the conversation with Tessa. It will not use anyone's real name or any information to identify you.

If you have any other questions, please talk to Tessa or a member of staff.

Your relative and/or support worker also knows about the project. They have been given a similar leaflet.

It is entirely your decision whether to take part.

If you don't want to take part, that is alright. You do not have to give a reason if you do not want to take part.

If you start and decide that you want to stop that is also fine, just let Tessa know or someone you feel comfortable talking to.

Whatever you decide, this will not affect the help you get here or anywhere else.

Thank you very much for your time

Confidentiality of the Data



Anonymised recordings and written versions of the conversations will be kept safe. Your name and details will NOT be stored. A note will be made of who has taken part and kept separately with the staff at [name of voluntary organization].

The recordings will be deleted following the examination of the research. The anonymous written versions will be kept for up to five years as they may help with future work.

Tessa will keep anonymous notes of all her contact with people involved in the research. Access to these notes is limited to the researcher, supervisors, and examiners.

If during our conversations Tessa is worried about yours, or anyone else's safety, she might need to share this with other people to ensure people remain safe. Tessa will always try and let you know if this was going to happen.

If you have any questions or concerns about how the study has been conducted, please contact the research supervisor, Dr Maria Castro.

Address: xxxxxxxxxxxxxxxxx

Telephone: xxxxxxxxxxxxxxxxx

Email: xxxxxxxxxxxxxxxxx

Thank you for your time. It is greatly appreciated.

SCHOOL OF PSYCHOLOGY

Dean: Professor Mark N. O. Davies, PhD, CPsychol, CBiol.



School of Psychology Professional Doctorate Programmes

To Whom It May Concern:

This is to confirm that the Professional Doctorate candidate named in the attached ethics approval is conducting research as part of the requirements of the Professional Doctorate programme on which he/she is enrolled.

The Research Ethics Committee of the School of Psychology, University of East London, has approved this candidate's research ethics application and he/she is therefore covered by the University's indemnity insurance policy while conducting the research. This policy should normally cover for any untoward event. The University does not offer 'no fault' cover, so in the event of an untoward occurrence leading to a claim against the institution, the claimant would be obliged to bring an action against the University and seek compensation through the courts.

As the candidate is a student of the University of East London, the University will act as the sponsor of his/her research. UEL will also fund expenses arising from the research, such as photocopying and postage.

Yours faithfully,

Dr. Mark Finn

Chair of the School of Psychology Ethics Sub-Committee

Stratford Campus, Water Lane, Stratford, London E15 4LZ
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e-mail: mno.davies@uel.ac.uk web: www.uel.ac.uk/psychology



The University of East London has campuses at London Docklands and Stratford
If you have any special access or communication requirements for your visit, please let us know. MINICOM 020 8223 2853



ETHICAL PRACTICE CHECKLIST (Professional Doctorates)

SUPERVISOR: Dr Maria Castro

ASSESSOR: Ian Wells

STUDENT: Tessa Hughes

DATE (sent to assessor): 12/03/2013

Proposed research topic: Stories of professional care: Narrative analysis of accounts from people with dementia

Course: Professional Doctorate in Clinical Psychology

1. Will free and informed consent of participants be obtained? **YES / NO**
2. If there is any deception is it justified? **YES / NO / N/A**
3. Will information obtained remain confidential? **YES / NO**
4. Will participants be made aware of their right to withdraw at any time? **YES / NO**
5. Will participants be adequately debriefed? **YES / NO**
6. If this study involves observation does it respect participants' privacy? **YES / NO / NA**
7. If the proposal involves participants whose free and informed consent may be in question (e.g. for reasons of age, mental or emotional incapacity), are they treated ethically? **YES / NO / NA**
8. Is procedure that might cause distress to participants ethical? **YES / NO / NA**
9. If there are inducements to take part in the project is this ethical? **YES / NO / NA**
10. If there are any other ethical issues involved, are they a problem? **YES / NO / NA**

APPROVED

YES	YES, PENDING MINOR CONDITIONS	NO
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MINOR CONDITIONS:

REASONS FOR NON APPROVAL:

Assessor initials: IW Date: 14/5/13

Appendix 9. Participant Biographies

Interview Participants

Mick – recently moved from what had been his inner-London home for decades to a nearby sheltered flat – introduced himself with reference to his qualifications, musical training, language skills and enjoyment of intellectual discussions. Throughout the interview, he weaved in details of his life story, including growing up with a mother who ‘battered’ [749] him daily. Mick left home as a young man and studied naval engineering, followed by a long career and world travel. He did not mention a family of his own, but discussed many long and important friendships, often with people ‘very high up’ [384]. The main caring relationship he discussed was with his care-coordinator, who he has known for several years.

Sid provided information about his diagnosis and care within the past couple of years for ‘early Alzheimer’s’. The couple have two middle-aged sons they see regularly, and a network of community connections. They remain within, and are deeply fond of, the area in which they both grew up. Sid talked of an active life, including military service, participation in a range of sports, and having always been a member of social clubs.

Flo has a close relationship with her daughter, who lives locally within the inner London borough in which Flo has lived all of her life, and visits daily, as do care workers, to assist with household chores and prepare meals,. Flo talked with pride of her roles as mother and wife, and as a working woman for a well-known company. With her husband no longer alive and a recent role-reversal (her daughter caring for her), these roles were always talked about in the past tense. Flo attends a different social club most weekdays at local churches and community centres, and has experienced recent cuts to the choice of these available locally. My understanding from Flo’s narrative was that these were for the local community of older adults, and not related to memory problems specifically.

Group Participants

- As well as being a mother of three, **Pam** held several jobs throughout her life, including customer service in the mobile canteen of a large film studio and in retail. She now lives with her husband and her daughter's family.

- **Thomas** talked of a long career and world travel with the merchant navy, prior to which he was raised in a rural area. He currently lives alone, keeping himself entertained and cooking.

- **Lionel** talked about a lifetime of loneliness, having never married or had children. He talked of a past including naval and army service and travel as a technician for an airline company.

- **Mrs Kalil** left Pakistan when newly married and pregnant to travel with her husband to his family in East Africa. She has lived in the UK for several decades, living now with her husband, who has physical care needs, with children and grandchildren locally who care for them to varying degrees.

- **George** worked as a lorry driver and is married with four children. He lives with his wife, whom he loves 'to bits' [Group 1, 429] and is particularly grateful to for her support with recent falls and hospital stays.

Appendix 10. Summary of analysis for group feedback

Summary Group findings¹¹

- **Collective stories of resistance** against being seen as passive. Talked of themselves as participants in relation to others. Want support, not 'care'.

Each story told pointed to how this might take shape. For example:

Mrs Kalil: ... my neighbour is er when they come to next me they are young and er now they are er come maturer or you know er er [1] old er middle aged and they give me respect like a mother, you know what mean? ... when er the scene er in my house is silent, no er type of noise and no hovering or in ... then they bang the wall ... they bang the wall, <Tessa: oh no> yeah because er they they I er bang in return the wall ... because they know I'm I'm still alive <Tessa: ooh I see, ok> <Pam: right> yeah, yeah <Tessa: So they check, so they bang the wall to check> yeah <Tessa: and you bang back (laughs) yeah ... so, so that's the, if I can't bang the wall then they come to back side door or come to door window knock the door or knock the window, if I can't reply then they call that ambulance or police then er if I faint along the floor or somewhere they are come and pick me, because the times for my er neighbours

Tessa: So that must be reassuring?

Mrs Kalil: Yeah they are like this because I look, I look after them also like mother, you know?

Tessa: Yes, ok

Mrs Kalil: So they give me respect, I give, I give love back you know? And so

Tessa: And do you look after other people? Or in your life have you looked after other people?

Pam: Oh yes many neighbours I've looked after

¹¹ Feedback prepared to meet needs of participants in a dementia context – i.e. clarity and concision were prioritised.

Tessa: Neighbours?

Mrs Kalil: Like me <Pam: yeah, umhm> my neighbour is the same like Pam's neighbours

Tessa: So let's, let's can you tell me any example of when you looked after a neighbour?

Pam: Well one person who's still on the end she got flooded one day <Tessa: Oh no> and run along to me as quick as she could ... 'What's the matter?' and she said 'Can you come and help me please I'm flooded out and I don't know where the water's coming from'. She had a burst, in the winter she had a burst tank <Mrs Kalil: mm> come right through her ceiling her kitchen and everything was flooded ... and her children are far out so it's no good contacting 'em cos they couldn't come easily yeah so we had to get the plumbers in to see to her

Gave me idea that 'care' needs to be genuine, fit with who you are, your culture etc and have role for you to do for others too. Support between people with memory problems, family, informal networks and professionals.

- **Positive effects of talking in group and telling own stories**

The groups demonstrated the processes between peers to enable communication abilities, and to develop sense of who you are and possibilities.

George: well, since last time we had a talk, I found it very interesting then

Tessa: Yeah, good?

George: It helped me a lot actually

Tessa: Having the conversations?

George: It's given me more confidence myself

George: Well, it means a lot, you know like I'm very hesitant at times, I have been so it's picking up something, that's what it's like, for a change

May simply need opportunities, and at times support, to share with others, e.g. who you are, stories and ideas

- **Limited reference to ‘dementia’ or memory.**

Imagined possibilities:

I pieced together stories to think about what is helpful, e.g. Lionel’s talking more confidently about who he is, e.g. outgoing, when others contributed to this story.

Lionel: I’m outgoing for a start. I don’t know whether Pam would decry this or not?

Tessa: (laughs) he’s saying he’s outgoing

Pam: Yeah, yeah he is

Tessa: So that helps

Pam: I’ve known him for a long while, interrupting, because when I first started the day centre in [nearby area] years ago ... he used to come over.

I met him and I just used to muck about with him

Tessa: Right, ok, so you’ve got quite a history?

Pam: yeah, yeah

Tells us something about what peer support can do – not just overcoming loneliness, but actually building up your sense of who you are?

Other things I noticed:

- In contrast to Thomas using his worldly experience to give him authority to talk (e.g. ‘*Oh, most things dear that I’ve come across, have been good*’), the women in the group drew upon key narratives of family life to develop their stories, and our understanding, of what is valued from others.

- Each can be understood within **life stories**, for example Pam has had, and to some extent continues to hold, a range of social roles (e.g. working woman, mother, neighbour etc) which support who she is. Different to Lionel, who needed the others in conversation to help him out more with who he is.

Appendix 11. Summary of feedback and contributions post-analysis

In regards to feedback from, and contribution to, analysis, all participants responded that they did not wish to make any further contributions after the research encounter, as they had 'said all I've got to say already', although would like to receive a summary of the outcome. Two participants, who made clear that they had exhausted their contribution to the subject, explicitly requested that I only contact them again with a written summary of the final report, and I was unable to contact three participants post-analysis: one had been discharged from the IDS, another had been admitted to hospital, and another did not respond to my attempts to contact him. All will be provided with a written summary of the research and opportunity to contribute feedback to ongoing dissemination of this research.